

**Bangor University**

## **DOCTOR OF PHILOSOPHY**

**Organ and tissue donation : factors influencing nurses' willingness to discuss post mortem donation wishes.**

Kent, Brigid Catherine.

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**Organ And Tissue Donation:  
Factors Influencing Nurses' Willingness To  
Discuss Post Mortem Donation Wishes.**

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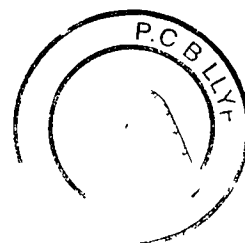
Brigid Catherine Kent

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-1998-



# Summary

Organ and Tissue Donation: Factors influencing nurses' willingness to discuss post mortem donation wishes.

By Brigid Catherine Kent

This thesis explores psychosocial factors influencing nurses' willingness to discuss post-mortem donation intentions with relatives of potential organ and tissue donors. The donation system, in the United Kingdom, is dependent upon the discussion of donation intentions, which often occur during a time of heightened emotion, following a declaration of death.

Nurses' reactions, and experiences, of this phenomenon, were explored, using a combined methodological approach, incorporating three separate but related studies. Two used surveys to quantitatively investigate qualified, and student, nurses' attitudes and knowledge to donation. One explored, qualitatively, nurses' experiences and responses pertaining to donor identification and donation discussion.

The results provide support for Ajzen's theory of planned behaviour, enhancing understanding of nurses' donation-related behaviour. Negative attitude, the influence of others, clinical area of work, past experience, socio-historical factors and intransigent fears and misconceptions, were found to influence intentions to undertake this aspect of care. A key underlying concept, to non-discussion behaviour, is proposed: protection, of the self, and of others. The addition of this concept appears to enhance the efficacy of Ajzen's model to explain nurses' donation discussion behaviour. Their inactivity was found to be impeding the donation of tissue, and organs, for transplantation.

Emerging from this investigation was an overwhelming expression of need for information about donor criteria and the donation process. Nurses' concerns need to be comprehensively addressed. They require reassurances that their fears, of anticipated reactions of relatives, patients, and colleagues will not be borne out in reality. Topics for further research are proposed.

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“Learning without thought is labour lost; thought  
without learning is perilous.”

Confucius

(Dictionary of Quotations, 1986, p.98)

# List of Contents

<b>LIST OF CONTENTS</b>	<b>VI</b>
<b>LIST OF TABLES</b>	<b>XVI</b>
<b>LIST OF FIGURES</b>	<b>XVIII</b>
<b>ACKNOWLEDGEMENTS</b>	<b>XIX</b>
<b>GLOSSARY OF TERMS</b>	<b>XX</b>
<b>INTRODUCTION</b>	<b>1</b>
<b>CHAPTER ONE: ORGANISATIONAL ASPECTS OF ORGAN AND TISSUE DONATION</b>	<b>4</b>
<b>Chapter overview</b>	<b>4</b>
<b>An overview of the history of transplantation</b>	<b>5</b>
<b>The donation system in the UK</b>	<b>7</b>
Organ donation and the law in England, Wales and Scotland	8
The donor card	9
<b>Alternative systems of donation</b>	<b>10</b>
Required-Request	10
Opting-Out	12
<b>The donation process</b>	<b>14</b>
Identification of the potential donor	15

Diagnosis of brain-stem death	16
Seeking consent for donation	18
<b>CHAPTER TWO: PSYCHOLOGICAL AND SOCIETAL FACTORS INFLUENCING ORGAN AND TISSUE DONATION</b>	<b>20</b>
<b>Chapter overview</b>	<b>20</b>
<b>Introduction</b>	<b>21</b>
<b>Roles assigned to health professionals during the donation process</b>	<b>22</b>
Roles to be assigned to nurses during the donation process	25
Rationalising and decision-making	31
<b>Health professionals' concerns related to the donation process</b>	<b>31</b>
Reservations about brain-stem death	33
Lack of confidence	33
Increasing relatives' distress	34
Fear of disfigurement	34
<b>Similarities in fears expressed by the public and health</b>	<b>35</b>
<b>Socialisation</b>	<b>37</b>
<b>Cost-benefit analysis</b>	<b>38</b>
<b>Risk taking</b>	<b>39</b>
<b>The bystander effect</b>	<b>41</b>
<b>Societal views on death and dying</b>	<b>43</b>
Death anxiety	44
Respect for the deceased	46
<b>Caring for the dying in critical care units</b>	<b>48</b>
Conflict arising from the aim of admission to an ICU	48
Importance of caring in the ICU	50
<b>Factors that encourage nurse participation in the donation process</b>	<b>51</b>
<b>Dissonance and nurses' donation behaviour</b>	<b>53</b>
<b>Avoidance as a coping mechanism</b>	<b>54</b>



<b>The stressors: the picture so far</b>	<b>57</b>
<b>Chapter summary</b>	<b>60</b>
<b>CHAPTER THREE: RATIONALE AND RESEARCH STATEMENT</b>	<b>62</b>
<b>Chapter overview</b>	<b>62</b>
<b>Rationale for the research</b>	<b>63</b>
<b>Statement of the research problem</b>	<b>65</b>
<b>Aims of the research</b>	<b>65</b>
<b>Research objectives</b>	<b>66</b>
Independent variables for Study One	67
Dependent variable for Study One	67
Reliability of the dependent variable	68
Validity of the dependent variable	69
<b>Theoretical framework</b>	<b>71</b>
The theory of planned behaviour	71
<b>Rationale for the combined approach</b>	<b>76</b>
<b>CHAPTER FOUR: RESEARCH METHODOLOGY</b>	<b>81</b>
<b>Chapter overview</b>	<b>81</b>
<b>Research design</b>	<b>82</b>
The target population	82
Seeking access for sampling	84
Approval for the research	85
Sampling in Study One	86
Data-collection: Study One	88
The research instruments	89
The Organ Donation Attitude Scale	89
Reliability of the organ donation attitude scale	92
Validity of the organ donation attitude scale	93
The Organ Donation and Transplantation Attitude and Knowledge Scale	96
Reliability and validity of the Organ Donation Attitude and Knowledge Scale	98

Data collection in Study One	99
Data analysis strategy for Study One	100
<b>Research design of Study Two: ‘talking about donation’</b>	<b>102</b>
Description of the researcher’s presuppositions	104
Study Two: sampling strategy	105
Influences on sample size	107
Trustworthiness in qualitative research	107
Semi-structured interviews	109
Planning and using the semi-structured interview method	109
Content of the final version of the interview schedule	110
Data collection in Study Two	112
Analysis of the interviews	112
Design of Study Three	113
Study Three: sampling	114
The students’ questionnaire	116
Reliability and validity of the students’ questionnaire	117
Data collection	117
Data analysis	118
<b>Chapter summary</b>	<b>119</b>
<b>CHAPTER FIVE: THE RESULTS OF STUDY ONE - QUALIFIED NURSES’ ATTITUDES, BELIEFS AND KNOWLEDGE LEVELS TOWARDS ORGAN AND TISSUE DONATION AND TRANSPLANTATION.</b>	<b>120</b>
<b>Chapter overview</b>	<b>120</b>
<b>Purpose of Study One</b>	<b>121</b>
<b>Study One: final sample details</b>	<b>122</b>
Profile of Study One respondents	122
Age	123
Gender	124
Qualifications	124
Post-Basic Qualifications	125
Clinical grading	126
Clinical Area	127
Religious Affiliation	129

<b>Attitudinal findings</b>	<b>130</b>
Regional variations in attitude scores	130
<b>Knowledge findings</b>	<b>133</b>
Overview of knowledge levels	133
The effect of place of work on knowledge scores	135
The association between knowledge and grade of nurse	136
Areas of good knowledge	137
Understanding of the diversity of organs that can be transplanted.	138
Payment for donations	138
Procedures determining brain stem death	138
Timing of death	139
Religious objections to donation	139
Areas of poor knowledge	139
Knowledge of exclusion criteria for organ and tissue donation	140
Coroners cases and the donation of organs and tissue	141
Cancer as an exclusion criteria for donation	142
<b>Assessment of donor potential</b>	<b>142</b>
Frequency of assessment for donor potential in clinical areas	143
<b>Protocols and potential donor assessment</b>	<b>145</b>
The influence of protocols on frequency of assessment for donation potential	147
<b>Previous experience of donation</b>	<b>148</b>
<b>Who should ask about donation?</b>	<b>148</b>
<b>Do you feel personally able to approach a family for consent for organ or tissue donation?</b>	<b>152</b>
The influence of experience, and skills, on nurses' perceptions of ability to discuss donation	154
Professional responsibility as a determinant for participation in donation request.	154
The influence of 'opting-in', on ability to participate in donation discussion	155
<b>The influence of personal and professional factors on self-perceptions of ability to ask for organ or tissue donation</b>	<b>157</b>
Gender, religious affiliation, qualifications and perceived ability to discuss donation	159
Age and perceived ability to discuss donation	159
Grade of the nurse and perceived ability to discuss donation	159
Clinical area and perceived ability to discuss donation	160
Previous experience of caring for a donor and perceived ability to discuss donation	160
Personal intentions towards donation	161

<b>The influence of attitudes on self-perception of ability to discuss donation</b>	<b>161</b>
Positive attitude and perceptions of ability to discuss donation	161
Negative attitude strength and perceived ability to discuss donation	162
Fear of causing distress and perceived ability to discuss donation	162
Fear of mutilation and perceived ability to discuss donation	164
The combined effect of psychosocial variables and ability to discuss donation	165
<b>The effect of knowledge on donation discussion ability</b>	<b>166</b>
Knowledge of the timing of death and perceived ability to discuss donation	167
Knowledge of the law and perceived ability to discuss donation	168
Knowledge of medical impartiality and perceived ability to discuss donation	168
Knowledge of types of transplants and perceived ability to discuss donation	168
<b>The factors having the most influence on perceived ability to discuss donation with relatives.</b>	<b>169</b>
Response bias	172
<b>Chapter summary</b>	<b>172</b>
<b>CHAPTER SIX: THE FINDINGS OF STUDY TWO “TALKING ABOUT DONATION”</b>	<b>176</b>
<b>Chapter overview</b>	<b>176</b>
<b>The purpose of Study Two</b>	<b>177</b>
Formation of the study group.	177
<b>The Interviewees</b>	<b>179</b>
Data collection	181
Analysis of the Interviews	183
Experiences of the donation process	184
‘Good experiences’ of donation	184
‘Coming to terms with the death’	185
‘Professional satisfaction’	187
‘Bad’ experiences of donation	188
‘Insufficient attention given to the family members’ feelings’.	189
‘When the donor is treated without respect’.	192
‘Words evoking negative mental images’.	194
‘Nurses’ subjectivity and donation experience’	194
Knowledge and understanding of the donation process	197

Perceived knowledge levels	197
Sources of knowledge	200
'Frustration due to lack of educational provision'	202
Participation in the donation process	204
'Meeting the patient's wishes'	204
'Being prepared'	208
'Protection'	210
Factors discouraging nurse participation in the donation process.	211
'Nurses' fears of anticipated reactions of the relatives' to donation discussion.'	212
'Nurses' fears of anticipated reactions of colleagues to the donation process'	214
'Fear of discussing death'	216
'Nurses' fears of their own reactions to death-discussion.'	221
Becoming involved: what the nurses felt able to do	223
'The nurse as a supporter of relatives and colleagues.'	223
'Supporting colleagues.'	224
'Overcoming traditional role differentiation'	225
'Supporting Relatives'	226
'Paving the way: preparing relatives for the possibility of donation'	228
'Covert activity: planting ideas in colleagues' minds.'	231
'The nurse as an educator on donation-related issues.'	234
<b>Chapter summary</b>	<b>236</b>
<b>CHAPTER SEVEN: THE FINDINGS FROM STUDY THREE: A COMPARISON OF STUDENT NURSES' AND REGISTERED NURSES' VIEWS ON ORGAN AND TISSUE DONATION.</b>	<b>239</b>
<b>Chapter overview</b>	<b>239</b>
<b>Introduction</b>	<b>240</b>
<b>Final sample details</b>	<b>241</b>
<b>Pre-registration student nurses' attitudinal results</b>	<b>242</b>
The influence of stage of training upon attitudes	244
<b>Student nurses' knowledge of donation and transplantation</b>	<b>245</b>
<b>Comparison of student nurses' attitudes, with those of the registered sample</b>	<b>247</b>
Attitudes and level of qualification	248

<b>Knowledge: a comparison of students' and registered nurses' scores.</b>	<b>249</b>
Brain-stem death and asystole	253
Timing of death and organ retrieval.	254
Involvement of the donor's doctor in the retrieval process.	255
Procedures for determining brain-stem death	255
The law and the sale of organs in the UK	256
Required request in the UK?	257
Religious groups and donation	257
<b>Implications arising from the comparisons made between student and registered nurses' attitude and knowledge scores.</b>	<b>258</b>
Educational issues for present day and future nurses.	261
<b>Chapter summary</b>	<b>266</b>
<b>CHAPTER EIGHT: LIMITATIONS OF THE RESEARCH</b>	<b>267</b>
<b>Chapter Overview</b>	<b>267</b>
<b>Intention versus reality</b>	<b>268</b>
Limitations on the research design	268
Restricting the focus	269
Accessing sites and samples	270
Limitations related to the data-collection tool used in Study One	271
Limitations associated with Study Two	274
Limitations related to Study Three	276
<b>Chapter summary</b>	<b>278</b>
Quality of the data	278
Investigator bias	279
Quality of the research process	279
Usefulness of the study findings	280
<b>CHAPTER NINE: RETURNING TO THEORY</b>	<b>281</b>
<b>Chapter overview</b>	<b>281</b>
<b>Factors influencing nurses' perceptions of ability to discuss donation</b>	<b>282</b>
Attitude towards donation discussion	282
Subjective norms	285

Perceived behavioural control	287
<b>Modifications to the theory of planned behaviour</b>	<b>290</b>
<b>Protection as a key variable in the model of discussion behaviour</b>	<b>293</b>
<b>Implications of the findings for nursing practice</b>	<b>296</b>
The development of local initiatives	300
Recommendations for education, practice and research	302
Recommendations for education	303
Recommendations for research	304
Recommendations for practice	305
<b>CHAPTER TEN: CONCLUSION</b>	<b>309</b>
<b>APPENDICES</b>	<b>321</b>
<b>Appendix 1: Criteria for organ And tissue donation.</b>	<b>322</b>
<b>Appendix 2: Brain stem death testing</b>	<b>323</b>
<b>Appendix 3: Letter from local ethics committee</b>	<b>324</b>
<b>Appendix 4: Letters authorising sites for data collection</b>	<b>325</b>
<b>Appendix 5: Letter authorising use of the Organ Donation Attitude Scale</b>	<b>326</b>
<b>Appendix 6: The modified Organ Donation Attitude Scale, used in this research.</b>	<b>327</b>
<b>Appendix 7: The Organ and Transplantation Attitude and Knowledge Scale.</b>	<b>328</b>
<b>Appendix 8: The information letter sent with the questionnaires.</b>	<b>329</b>
<b>Appendix 9: The interview schedule</b>	<b>330</b>
<b>Appendix 10: The students' questionnaire</b>	<b>331</b>
<b>Appendix 11: Information related to deaths in hospital</b>	<b>332</b>
<b>Appendix 12: Summary of student nurses' knowledge responses.</b>	<b>333</b>
<b>Appendix 13: Enquiring about donation intentions: pilot study</b>	<b>336</b>
A pilot scheme for developing confidence in donation discussion ability.	337

**REFERENCES**

**340**



## List of Tables

<b>Table 1.1: Stages of the Donation Process.....</b>	<b>15</b>
<b>Table 2.1: Nurses' roles in the Donation Process.....</b>	<b>26</b>
<b>Table 2.2: Health professionals' reservations about the Donation Process. ....</b>	<b>32</b>
<b>Table 2.3: Stressors experienced by nurses caring for organ donors and their families .....</b>	<b>57</b>
<b>Table 4.1: Characteristics of the target population .....</b>	<b>83</b>
<b>Table 4.2: Study Three sample population of Diploma in Nursing student cohorts (N = 224) .....</b>	<b>115</b>
<b>Table 5.1: Study One - Response.....</b>	<b>122</b>
<b>Table 5.2: Clinical Grade of respondents compared with sample population... </b>	<b>127</b>
<b>Table 5.3: Positive and Negative Attitude Scores .....</b>	<b>130</b>
<b>Table 5.4: Regional positive and negative attitude scores .....</b>	<b>131</b>
<b>Table 5.5: Positive and negative attitudinal groups.....</b>	<b>132</b>
<b>Table 5.6: Knowledge scores showing regional variations. ....</b>	<b>133</b>
<b>Table 5.7: Correlations between knowledge and area of work, clinical grade and age .....</b>	<b>135</b>
<b>Table 5.8: Correlation between knowledge and perceptions of ability to discuss donation issues, showing regional and grade variations.....</b>	<b>137</b>
<b>Table 5.9: High scoring topics, showing regional variations.....</b>	<b>137</b>
<b>Table 5.10: Low scoring topics, showing regional variations.....</b>	<b>140</b>
<b>Table 5.11: Responses to the tissue donation exclusion criteria.....</b>	<b>140</b>
<b>Table 5.12: responses to organ donation exclusion criteria.....</b>	<b>141</b>
<b>Table 5.13: Qualities of the person making a donation request. ....</b>	<b>151</b>
<b>Table 5.14: Perceptions of ability to discuss donation - underlying constructs. ....</b>	<b>153</b>
<b>Table 5.15: Correlation between changes to the donation system and perceived ability to discuss donation. ....</b>	<b>156</b>
<b>Table 5.16: Correlation between personal, professional and attitudinal variables, and self-perception of ability to discuss donation.....</b>	<b>158</b>
<b>Table 5.17: Perceived ability to discuss donation by area of work .....</b>	<b>160</b>
<b>Table 5.18: Correlation between previous experience and fear of causing distress.....</b>	<b>163</b>
<b>Table 5.19: Logistic regression: prediction of the likelihood of the nurse feeling able to discuss donation with bereaved relatives - using psychosocial variables as predictors. ....</b>	<b>165</b>
<b>Table 5.20: Correlation between knowledge and perceived ability to discuss donation .....</b>	<b>167</b>
<b>Table 5.21: Logistic regression: prediction of likelihood of being able to discuss donation, showing overall and sub-sample results.....</b>	<b>170</b>
<b>Table 6.1: Grade profile of the sample population for Study 2.....</b>	<b>178</b>
<b>Table 6.2: The interviewees' grade and clinical area of work. ....</b>	<b>180</b>

<b>Table 7.1: Student sample, showing response.....</b>	<b>242</b>
<b>Table 7.2: Individual student cohort attitude scores .....</b>	<b>243</b>
<b>Table 7.3: Significant correlations between specific attitudinal variables and stage of training .....</b>	<b>244</b>
<b>Table 7.4: A summary of the student cohorts' knowledge results .....</b>	<b>246</b>
<b>Table 7.6: A comparison of percentage knowledge scores between student and registered nurses.....</b>	<b>250</b>
<b>Table 7.7: Comparisons of knowledge responses between, student and registered nurses, showing % correct and % incorrect. ....</b>	<b>252</b>
<b>Table 7.8: Responses to “ A brain-stem dead patient is not dead until the heart stops.” .....</b>	<b>253</b>
<b>Table 7.9: It is illegal to sell organs in the UK, showing sub-groups' responses. ....</b>	<b>256</b>
<b>Appendix 12: Student cohorts' correct answers, showing stage of training.....</b>	<b>334</b>

## List of Figures

<b>Figure 2.1: Quint’s model of caring for the dying .....</b>	<b>55</b>
<b>Figure 2.2: McClement’s revised model of caring for the dying in ICU.....</b>	<b>56</b>
<b>Figure 3.1: Theory of Reasoned Action (from Ajzen &amp; Madden, 1986).....</b>	<b>72</b>
<b>Figure 3.2: Theory of Planned Behaviour (from Ajzen &amp; Madden, 1986).....</b>	<b>73</b>
<b>Figure 5.1: Age profile showing regional variations.....</b>	<b>123</b>
<b>Figure 5.2: Post-registration qualifications (showing regional variations).....</b>	<b>125</b>
<b>Figure 5.3: Sample showing clinical area of work .....</b>	<b>128</b>
<b>Figure 5.4: Clinical area of sample, showing regional variations. ....</b>	<b>128</b>
<b>Figure 5.5: Knowledge scores for the two regional sub-groups. ....</b>	<b>134</b>
<b>Figure 5.6: Knowledge scores by clinical area. ....</b>	<b>136</b>
<b>Figure 5.7: Frequency of assessment for donor potential, showing regional variations. ....</b>	<b>143</b>
<b>Figure 5.8: Frequency of assessment in clinical areas. ....</b>	<b>144</b>
<b>Figure 5.9: Nurses’ awareness of protocols for organ and tissue donation .....</b>	<b>146</b>
<b>Figure 5.10: Who is the most appropriate person to discuss donation? .....</b>	<b>149</b>
<b>Figure 5.11: Nurses’ perceptions of ability to discuss donation .....</b>	<b>153</b>
<b>Figure 5.12: Nurses’ perceptions that donation request offend the potential donor family.....</b>	<b>163</b>
<b>Figure 7.1: Mean positive attitude scores - student and qualified nurses.....</b>	<b>248</b>
<b>Figure 9.1: Model of discussion behaviour .....</b>	<b>290</b>

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## Glossary of Terms

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**Cadaveric donation:** Removal of organs or tissue from a dead donor.

**Live donation:** Removal of organs or tissue from a living donor.

**Brain-stem death:** irreversible loss of brain stem function, determined by the exclusion of reversible causes of loss of function, together with a context of irremediable structural brain damage (Pallis, 1984)

**Donation process:** the events that determine the availability of organs and tissue for transplantation.

**Donor identification:** recognition of a person's potential for cadaveric organ, or tissue, donation.

**Donation discussion:** activity to determine the wishes of patients, or relatives, in relation to the donation of organs and tissue after death.

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## Introduction

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In the United Kingdom (UK) and other Western countries, transplantation surgery, using human organs and tissue, has become established treatment for a variety of end-stage diseases including heart, renal, liver and respiratory disease. Advances in surgical techniques, and the introduction of the anti-rejection drug, Cyclosporin, have lengthened the survival period, after transplant surgery. Demand for human tissue and organ transplants has been seen to increase annually. Presently, it outstrips supply, as reflected in the annual statistics, produced by the United Kingdom Transplant Support Services Authority (UKTSSA, 1997). Predictions indicate that this situation will remain for the foreseeable future (New et al., 1994).

Transplantation surgery will remain important as a treatment for many people, world-wide, because, presently, there is no viable alternative. The numbers of people waiting for these procedures are not insignificant and cannot be easily disregarded, as the following figures indicate: in the last year alone, in the UK and Ireland, in excess of 4000 people were waiting for a kidney transplant (UKTSSA, 1997). Concern over this issue has led to a Minister, responsible for transplantation issues, being appointed, and research monies have been directed towards further exploration of a solution.

The King's Fund Institute, London, recently focused on the increasing problem of rising waiting lists for transplant surgery (New et al., 1994). The significance of health professionals' contribution in the donation process was acknowledged in this research. However, this information, although useful and enlightening, is of little

value, unless the recommendations made by the investigating organisations are acted on.

The conclusions reached by New et al. (1994) were not unexpected. Researchers have been exploring the behaviours related to organ and tissue donation for several decades, particularly in North America. The foci, in the past, have been on motives for personal donation and willingness to donate among the general population, the systems used to acquire organs for transplantation, and on the behaviour of health professionals to the whole concept of organ donation and transplantation.

Extensive dialogue, with medical, nursing and other professionals involved in health care in the UK, revealed that, despite the research, there remains no consensus on the extent of health professionals' participation, or the roles that they may have, in this aspect of health care. The dearth of substantial studies emanating from the UK may be compounding this problem.

The process of organ donation begins with the identification of the person as a potential donor and concludes with the outcome of a request for donation. This outcome may be the retrieval, and subsequent transplantation, of organs or tissue. Alternatively, the relatives of the potential donor may decide, for whatever reason, that donation is not an appropriate outcome for them.

In Chapters One and Two, the literature identifying factors implicated in adding to, or easing, anxieties of health professional, and the general public, in relation to organ and tissue donation will be discussed. So too will the factors that affect the outcome of donation requests.

North American studies have stressed the positive effect that nurses can have on the outcome of the discussion stage of the donation process. However, there is a dearth of scientific evidence, at present, to support or disregard this phenomenon in the UK. Nurses have a duty to elicit and then communicate the wishes of the person in their

care (UKCC, 1992a). These wishes include general and specific post-mortem intentions, such as spiritual issues and those related to organ or tissue donation. There is anecdotal evidence to suggest that this duty is not recognised or that, alternatively, nurses avoid such actions. Examination of local nursing documentation, used to assess patients' needs, revealed the lack of attention paid to post-mortem intentions. The identification of patients' post-mortem donation intentions is, therefore, a key issue to be explored in this thesis.

Chapters Three and Four address the aims and objectives of the research, and relate these to the key points to emerge from the reviewed literature.

Chapters Five, Six and Seven contain the results of data-collections in the three studies that form the content of this thesis. Although each study is a separate exploration of issues related to nurse participation in donor identification and donation discussion phases of the donation process, the interrelationships between the investigations are made explicit in these chapters.

The limitations of the research will be highlighted in Chapter Eight. Few research investigations are flawless. Identification of the issues that can affect the usefulness of the findings form an essential aspect of the scientific process.

In Chapter Nine, Ajzen's theory of planned behaviour is reviewed, in light of the findings, to evaluate its efficacy in explaining, or predicting, nurses' behaviour related to the donation process. An ensuing discussion about the implications of the findings for practice completes the research process, with recommendations being suggested for future research, and for nursing practice.



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## Chapter One: Organisational Aspects of Organ and Tissue Donation

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### Chapter overview

This is the first of two chapters reviewing the literature related to the supply of donated human organs and tissue for transplantation and will focus on the organisational aspects of the donation process. Different systems of donation are utilised throughout the world. These will be discussed and their relevance, to the current investigation, made explicit. The process of donation, and the influence that the various stages has been found to have on health professionals' behaviour and the availability of donated organs and tissue, will also be discussed, in light of the available literature. This introduces the psychosocial issues influencing health professionals' behaviour, related to the donation process, that form the focus of Chapter Two.

## **An overview of the history of transplantation**

The 20<sup>th</sup> century will be recognised for the developments in transplantation surgery. Due to medical and surgical advances, transplant operations are now 'routine' procedures in many specialist hospitals in the UK. The transplantation of human tissue, from one person into another, has been hailed as "a marvel of modern technology" (Shanteau and Harris, 1992) and as "miracle" (Sharp, 1995). This contrasts with the position, as recent as thirty years ago, when rejection by the host immune system commonly occurred, resulting in poor prognoses and high mortality rates.

The first successes in human transplant surgery came at the beginning of the 20th century and involved the transplantation of corneal tissue (Wilson and Bourne, 1989). Human organ transplants, however, were not reported until 1954, when the first successful renal transplant was performed (UKTSSA, 1994). This case marked the point at which transplantation surgery became a viable procedure. The recipient survived for eight years before dying of a heart attack.

By the 1960s, developments in the field of immunosuppression therapy had reduced the incidence of rejection. Tissue-typing techniques had, also, become more advanced, enabling recipients to receive histocompatible organs which further reduced rejection. In the 1980s, Cyclosporin A, a new immunosuppressive agent, was licensed for use in the UK (UKTSSA, 1994). The use of this drug led to great improvements in all organ transplant survival rates.

Presently, transplantation is cost effective and a beneficial treatment. In the absence of transplantation, individuals suffering from end-stage heart, or liver disease, face the prospects of early death. For those suffering from end-stage renal disease, there are other options available, such as haemodialysis or peritoneal dialysis. However,

the waiting lists figures, supplied by the UKTSSA, suggest that the preferred option, for many patients, is transplantation.

The demand for organ transplants exceeds supply. In the period 1 January 1997 to 31 March 1997, there were 6266 patients waiting for a solid organ transplant (e.g. heart, lung, kidney, liver, pancreas, combined heart and lung, or combined kidney and pancreas), an increase of 4% on previous figures (UKTSSA, 1997). During the same period, the number of transplants being performed, using organs from cadaveric (see Glossary of Terms) rather than live donors, remained static. The rise in demand for transplantation surgery may be due, in part, to greater flexibility within the transplant assessment system, when compared with the rigid protocols used when transplantation programmes were in their infancy. When the procedures were seen as experimental, and the future of the programmes depended on high one year survival rates, the criteria for acceptance on to the waiting list were very specific. Consequently, the waiting lists comprised of the most suitable candidates, who stood the best chance of sustained recovery following the procedure (Turcotte, 1992). Older, sicker people are now being accepted on to transplant programmes with resultant increases in the size of the waiting lists.

The time that one spends on the transplant waiting list varies according to a number of factors, such as, stage and type of illness, state of health, blood group, tissue type, age and body size, as well as the type of organ required. For some individuals, the wait can be lengthy and a transplant cannot be assured. Statistics, produced by UKTSSA (1996), indicate that, during 1995, 48 heart, 30 heart/lung, and 51 lung patients died whilst on the active waiting list for a transplant, reflecting a death rate of approximately 17%.

The majority of donated human organs and tissue are retrieved from heart-beating cadavers. Only a small percentage of human organs transplanted are derived from a live source such as a parent or sibling. In 1995 there were only 183 live donations of organs transplanted in the UK and Ireland, compared to 2978 cadaveric donations (UKTSSA, 1996). Recommendations, approved by the British Transplantation

Society in April 1986, state that living donors should be considered as the exception, rather than the norm (IME, 1986).

If the needs of those who are awaiting transplantation surgery are to be met, it is important to consider the effect that organisational, psychological and societal factors may have on the availability of transplantable organs and tissue. Understanding the process by which organs and tissue become available for transplantation helps to contextualise the interrelationships with psychosocial and societal issues that may also be influencing the availability of donated human parts. The process of donation, used in the UK, will be discussed next.

## **The donation system in the UK**

The UK's system of donation is frequently referred to as 'Opting-In'. The primary principle underpinning this is voluntarism. Donated organs and tissue are seen as 'gifts' and there is no obligation imposed on this giving. The system has been criticised recently for its part in contributing to the shortfall in the supply of donated organs and tissue (New et al., 1994).

'Opting-In' is named thus because the individual decides to opt into the system to donate human parts after death through the use of a card or some other similar scheme. In a discussion paper focusing on the various transplant laws and related transplant activity in Europe, Land and Cohen (1992) commented that a more accurate name for the donation system in the UK would be 'informed consent'. 'Opting-in' implies that the individual has the sole authority to decide to offer human parts for transplantation, as indicated by the signature on the donor card, or registration form. This autonomy, however, is questioned by Land and Cohen (1992) since it is extremely unusual for a donation to proceed, in the UK, without discussing the issue with the deceased's relatives, in accordance with the Human Tissue Act of 1961.

## Organ donation and the law in England, Wales and Scotland

The Human Tissue Act of 1961 enabled body parts to be removed, from cadavers, for 'therapeutic purposes', medical examination, research and for post-mortem examination. The Act stated, for the first time in the UK, that a person, lawfully in possession of a body, could authorise use of the body parts after death. 'Reasonable inquiries' were required to be made to discover if the deceased had expressed objections to the removal of tissues during his, or her, lifetime and to uncover any such objections by the relatives of the deceased. It is this clause, in the 1961 Act, which has led to relatives of the potential donor being consulted over a donation decision, even though the deceased had carried a donor card. It is also the reason why Land and Cohen (1992) argue that the system's name should be altered to one of informed consent.

Whilst discussing the legal and ethical issues of transplantation, Ian Kennedy (1992b) commented that there may be a case for legal action if the person, who was lawfully in possession of the body, failed to consult relatives of the deceased and discover any objection. A claim for liability in tort could be brought if nervous shock and distress resulted from a retrieval without the consent of the deceased's spouse or close relatives. Kennedy goes further to suggest that the Law needs reforming. In his opinion, the framework of the Human Tissue Act and the difficulties that arise in its interpretation, have added to the shortage of transplantable organs in the UK. These, he argues, encourage doctors to tread cautiously and favour non-retrieval of tissue.

Despite Kennedy's concerns, however, the present system appears to have the support of the general public (New et al., 1994). The vast majority, of the British public, was found to be in favour of donating organs after death (7 out of 10 people questioned). Nevertheless, this popularity is not reflected in the percentage of donor card carriers reported, by the King's Fund Institute of London, to be around 30% of the population (New et al., 1994). This proportion of card carriers appeared to be higher in the UK than in Germany and Holland (2% and 18% respectively of the population have donor cards). Research from the USA suggests that the incidence of

donor card possession reflects that of the UK (Evans and Manninen, 1988). The general population, although in favour of the current system of donation in the UK, appear to be less inclined to convey their wishes by signing and carrying a donor card. Despite this, the Donor Card is a familiar sight in the UK and could be called a trademark for transplantation. In the following section is a brief discussion about its history and the effect that it can have on the decision to donate organs and tissue.

## The donor card

The Donor Card was first introduced nationally in 1977. Since 1994, it has been supported by a computer database, the NHS Organ Donor Register, introduced to improve the channels of communication, yet this too has its problems. Restrictions have been placed on access to the Organ Donor Register. Consequently, not all health professionals can use the database to inquire if a person's name is on the register. Contact has to be made via the transplant co-ordinator who is authorised to access the computerised register (Warren, 1996b). This mechanism, therefore, requires health professionals to identify a person as a potential donor, before liaising with the transplant co-ordinator, even though the patient's wishes may be unknown. Currently, there is no legal requirement for health professionals to assess a patient's suitability for organ or tissue donation, which may influence the health professionals' subsequent behaviour. The opportunity for donation arises at a time when the potential donor is very close to death, or deceased, and unable to communicate post-mortem intentions. There may be no evidence of a donor card among the potential donor's possessions, and the family may not know the person's intentions.

There is evidence to suggest that knowledge of a person's intention to donate organs after death has a positive effect on the willingness of relatives to consent to donation when a request is made to them. The OPCS survey, reported by New et al. (1994), found that agreement to a hypothetical donation request increased, from 58% to 95%, when respondents were told that the person, who had died, carried a card indicating a wish to donate organs after death. Respondents might have given socially desirable responses to these questions (Oppenheim, 1992), however, there are other studies

that support these findings. (Pelletier, 1992; Savaria, Rovelli, and Schweizer, 1990; Sque, 1996). The most recent research, cited here, carried out by Sque (1996), focused on the feelings experienced by the families of organ donors, in the UK, during the hospitalisation and subsequent donation of organs for transplantation. Knowing the wishes of the deceased appears to have helped these families to decide about organ donation.

Despite the support from the general public, it has been suggested that changes to the system of donation are required because it does not appear to be meeting the rising demand for transplantable human organs and tissue. A number of papers in the journal, 'Transplantation Proceedings', serve to illustrate the level of interest in examining the efficacy of different systems of donation (Cohen, 1992; Evans and Manninen, 1988; Gnant et al., 1991; Johnson, 1990; Keyserlingk, 1990; Land and Cohen, 1992; Sadler, 1992; Sells, 1993; Turcotte, 1992; Virnig and Caplan, 1992). The alternative systems will now be discussed, to determine the effect that they have had on reducing transplantation waiting lists, and waiting time.

## **Alternative systems of donation**

Kennedy (1992a) supports a move away from 'opting-in' to one in which there is less scope for personal altruistic acts and a greater use of the law to encourage the discussion of donation with the deceased's family members. There are predominantly two approaches that would meet Kennedy's demands: 'Required-request', and 'Opting-out'. These will be discussed now beginning with 'required-request'.

### **Required-Request**

This approach requires that:

- health professionals involved in the care of a potential donor talk to the relatives to inquire about the post-mortem donation wishes of the patient or the family (Davis, 1989), and
- a referral is made to the transplant co-ordinator, or procurement officer as they are known in the USA, when the potential donor dies.

Required-request retains elements of voluntarism, which underpins the system in the UK, whilst minimising the effect of the unpredictability of request by health professionals that can occur in the 'opt-in' system (Riggulsford, 1992; Siminoff, Arnold, and Caplan, 1995; Smith-Brew and Yanai, 1996). Required-request has been adopted in many of the states in the USA. The Uniform Anatomical Gift Act (UAGA) passed in the USA in 1968, paved the way for legislation authorising the adoption of this system of donation in individual states of the USA: 45 states currently subscribe to this approach. New et al. (1994) explored the possibility of introducing this type of approach into the UK. However, the authors concluded that there was no evidence to suggest that this approach significantly increased donation rates when compared to those arising from the 'opting-in' system (New et al., 1994).

Required-request is an attempt to standardise the identification and request stages of the donation process, thereby, minimising subjective decision-making by health professionals. This has the advantage of lessening of the strain on health professional and the bereaved relatives since the decision to raise the subject of donation is not taken by one individual (Caplan, 1988). A legal requirement prompts the request, thus removing the onus of responsibility from the health professional. New et al. (1994), however, expressed concern that this approach to donation may be too prescriptive, leaving little room for professional judgement. Virnig and Caplan (1992) commented that, in the USA, the law provides little guidance for the implementation of this requirement for donation request. Consequently, it is open to interpretation by individual hospitals, and health professionals, which has led to inconsistencies in local policies.



Anecdotal reports suggest that inexperienced requesters, who have had little training in approaching relatives, are asking for organs to be donated. The effect of such actions can be traumatic and long-lasting (Davis, 1989). She argues that this practice is unethical, as it can leave the relatives psychologically traumatised if a request is made before the family has begun to understand the finality of the patient's condition. The manner, and personal views, of the requester, and the timing of the request have been implicated as affecting the outcome of the request for organ donation (Birkimer et al., 1994; Carbary, 1987; Haney, 1973).

There has been much debate about the advantages and disadvantages of this system of donation (Davis, 1989). Caplan (1988) urges that the voluntary nature of donation should be retained, thus allowing relatives the opportunity to object to any donation plans. However, he supports the view that the onus for the decision to make a request should be removed from the individual health professional and, instead, determined by Law (Caplan, 1988). Others, though, oppose the imposition of such legislation and argue that there are occasions when it is not appropriate to ask about post-mortem intentions, since it might be detrimental for the patient or the family at that time (Watkinson, 1995).

The Opting-Out system of donation, which contrasts with that used in the UK, will be discussed now.

## **Opting-Out**

The system of 'opting-out' requires adults to decide, for themselves, whether or not they want to become cadaveric organ donors (Spital, 1996). The control over donation is taken away from the family and given back to the individual. This type of legislation would require all of the adult population, in the UK, to make a decision about donation and any objectors would be noted. In the absence of any other instructions, the relatives of a potential donor would not be able to prevent the removal of organs after death. Critics of 'opting-out' have commented that it discards the principles of liberty and voluntarism (Sells, 1979; Veatch, 1991). Advocates of

this system argue that, by removing the stress of decision-making from the families of potential donors, the objection rate will fall, thus increasing the availability of organs for transplantation (Michielsen, 1996).

The opting-out system eliminates the need for a request stage of the donation process, identified as a major problem by several researchers (Kolata, 1983; Malecki, 1987; Riggulsford, 1992; Robinette et al., 1985; Savaria, Rovelli, and Schweizer, 1990; Siminoff, Arnold, and Caplan, 1995; Wakeford and Stepney, 1989). Therefore, the adoption of this system would, it is argued, simultaneously remove a barrier to donation.

‘Opting-out’ is the system adopted by Belgium, Austria, Norway, parts of Spain, and Portugal (Land and Cohen, 1992). According to Michielsen (1996) an 86% increase, in cadaveric kidney donation, followed the introduction of the opting-out legislation, which is reported to have been sustained. Many factors and events, however, determine the actual organ retrieval rate, and the opting-out system is just one of them. Other factors include: population density in the country; age stratification; the incidence of road traffic accidents (one of the main precursors to brain-stem death and organ donation in the UK, (UKTSSA, 1996)); and the provision of intensive care facilities within the country (most potential donors are cared for in the intensive care area because of the need for artificial ventilation facilities: inability to breathe spontaneously is a symptom of severe head injury and is tested before a diagnosis of brain-stem death can be reached).

The observed effect of ‘opting-out’ laws in Belgium prompted Wing (1996) to ask if the UK should follow Belgium’s lead. Similar questions have been asked in the USA (Kolata, 1983; Spital, 1996). Kolata considered the adoption of ‘opting-out’ to be a ‘drastic step’, but pointed out that the success of transplant surgery has created a demand that shows no sign of waning.

Regardless of the system of donation adopted, or the viability of other options, such as inducements, including payment, the product, or focus, of the approach is the same. The retrieval of human organs or tissue for transplantation is achieved by progress through a series of stages. This will be referred to, during this thesis, as the donation process, details of which will be described now.

## **The donation process**

The process of donating organs, and tissue, is guided, in the UK, by a Code of Practice, drawn up in 1979 and revised in 1983, by the Health Departments of the UK including Northern Ireland (Dept. of Health (DoH), 1983). The Code clarifies the procedures involved in the supply of organs for transplantation, and reflects the legal requirements of the 1961 Human Tissue Act. This was amended in 1990 to address the increasing incidence of HIV infection, and requires that all potential donors are now tested for HIV infection (DoH, 1990).

The main stages of the donation process are outlined in Table 1.1. Some variance is permitted by the Code of Practice (1983, p.5), and this tends to occur at the referral stage of the process. Some transplant co-ordinators advocate referral as soon as the possibility of donation arises, which is the general policy in the USA (Savaria and Swanson, 1995), while others will advise hospitals to wait until the first set of brain-stem tests have been completed. From personal observations, the latter is more common in the UK.

**Table 1.1: Stages of the Donation Process**

<i>Table 1.1: Stages of the donation process</i>
Potential donor identification
Breaking news of patient's poor prognosis to relatives
Brain-stem death testing - organ donors only - 1st test
Relatives told of the test results
Discussion of donation intentions with relatives
Provisional referral to transplant co-ordinator
Permission for donation of organs and/or tissue
2nd set of brain-stem tests
Declaration of death - relatives informed
Donor maintenance - organ donor only
Retrieval of donated parts
Post-donation contact with relatives and health professionals

Only those stages that are particularly pertinent to the present research will be discussed here. They include the identification of the potential donor; diagnosis of brain-stem death; and the discussion of donation issues with the relatives, to obtain consent.

## Identification of the potential donor

The identification of the patients as a potential donor is a crucial stage in the organ and tissue donation process. It has been identified as a major stumbling block for the supply of organs for transplantation (Savaria and Swanson, 1995). This stage is dependent on health professionals being aware of the criteria for donation, which may vary slightly according to the requirements of individual transplant centres (for details of the general criteria for organ and tissue donation, see Appendix 1). For this reason, it is important that the clinical areas have a good working relationship with the local transplant co-ordinator. If health professional fail to recognise the potential for donation, the process would not progress, unless the family of the critically ill patient conveyed donation wishes. The shift in responsibility, from the health professional to the family, is a practice that has been called ethically and morally unsound (Spital, 1996).

For the process of donation to proceed beyond the initial identification stage, suitability for donation must be further assessed. A key aspect of the assessment is the determination that death has occurred. In the UK, this usually entails assessing the function of the brain-stem, brief details of which will be presented now.

## **Diagnosis of brain-stem death**

Brain-stem death is defined, by Pallis (1984 p.2), as ‘a state in which there is irreversible loss of the capacity for consciousness combined with the irreversible loss of the capacity to breathe (and hence to maintain a heart beat).’ This diagnosis of death was endorsed by the Conference of Medical Royal Colleges and their Faculties in the UK, in 1976 and 1979, and forms the basis for the 1983 Code of Practice for the Removal of Organs for Transplantation (DoH, 1983 p.11).

Diagnosis of brain-stem death follows very strict procedures, laid out in the Code of Practice. These are aimed at eliminating error. An initial diagnosis must be confirmed by second testing, carried out independently of the first. Following confirmation of the initial diagnosis, the ventilatory support would be withdrawn should the patient not be a candidate for organ donation. However, if organ donation is to ensue, the support is maintained to ensure that the organs and tissue remain in optimal condition (see Appendix 2 for details of the brain-stem death testing).

The concept of brain-stem death can be difficult to comprehend as the appearance of the patient, following the declaration of death, continues to resemble a sleeping person. Nursing a person who has been declared dead, yet appears ‘alive’, was cited as difficult by experienced nursing staff (Watkinson, 1995). Such concerns, about some aspects of brain-stem death testing, are supported by findings from other studies (Kiberd and Kiberd, 1992; Matten et al., 1991; Sophie et al., 1983; Soukup, 1991). It has been suggested that the family of the deceased, as well as the health professionals caring for that person, find adjustment to the diagnosis and the finality of the situation, difficult (Soukup, 1991; Sque, 1996).

Patients diagnosed as brain-stem dead, accounted for 10% of all deaths in intensive care units (ICUs), audited in a study commissioned by the Department of Health in 1989 -1990 (Gore, Cable, and Holland, 1992). This study found that relatively few of the patients who die in intensive care units each year, estimated from the audit to be around thirteen thousand, could be considered for organ donation. Unpublished data, collated by the transplant co-ordinator for North Wales, indicates that, on average, there are fewer than 6 organ donations annually, from each of the ICUs in that region (personal communication, Bentley, 1997). Organ donors are therefore a rarity in most general intensive care units, and nurses, working in general areas, would have few opportunities to become involved in such care.

One would expect to find low levels of awareness, of the criteria for organ and tissue donation, among health professionals in the units where the incidence of donation is low. However, Watkinson (1995) found that critical care nurses, working in 4 general ICUs in England, had, in general, a good understanding of the issues related to brain-stem death and donation. These findings may reflect the high rate of solid organ donation from brain-stem dead patients, noted by Gore et al (1992), in the region where Watkinson was based.

Unlike organ donation, human tissue for donation is avascular in structure and, consequently, retrieval can take place after asystole has occurred. Therefore, the brain-stem death testing is not a pre-requisite for tissue donation. This should mean that the visual and cognitive stimuli are less dissonant, resulting in fewer concerns about the process. However, Gore et al. (1992) found that less than 4% of potential donors of corneal tissue were recognised as such by health professionals. In an exploratory study, Kent (Kent and Owens, 1995; Kent, 1991). suggested that personal dislike of the concept may be a contributory factor, suppressing the discussion of donation issues with relatives. This phase of the donation process will be elaborated upon now.

## Seeking consent for donation

This stage of the donation process, seeking consent for donation, be it organ or tissue, has been called one of the most difficult aspects of the process, even for those who support donation (Savaria and Swanson, 1995). The Code of Practice recommends that relatives' views be taken into account (DoH, 1983 p.8). However, the thought of performing this role appears to evoke anxiety that is deep-seated and remains, according to the literature, a barrier to donation world-wide (Robinette et al., 1985; Spital, 1991; Spital, 1996; Tabak, 1994). Health professionals are concerned about the negative impact that the discussion will have on the family's distress. This persists despite several research studies that have found that the opposite occurs, particularly longer-term (Malecki and Hoffman, 1987; Pelletier, 1993; Sque, 1996). The issue of psychosocial barriers to donation will be discussed further in Chapter Two.

The Code of Practice for Transplantation does not stipulate who should discuss donation except to state that it should be the person who is best qualified given the individual circumstances of each case (DoH, 1983 p.8). Seeking consent appears to be affected by the competency of the requester in these key areas: knowledge, experience at talking to relatives, and good interpersonal skills. Consequently, a number of research studies have concluded that nurses are best suited to perform this role (Bisnaire, 1988; Cambria and Paulik, 1986; Carbary, 1987; Coupe, 1990; Ferdinand, 1994; Hart, 1986; Malecki, 1987; Robinette et al., 1985). However, saying that nurses are ideally placed to do this, and converting those thoughts to practice appear to be difficult to reconcile.

The organisational aspects of donation have been shown to affect the availability to donated organs and tissue for transplantation. However, not all the blame for this mismatch between supply and demand can be put down, solely, to the opting-in system of donation. Other systems in use elsewhere in the world have reported similar shortages in transplantable organs and tissue. Therefore, the exploration needs to be expanded to discover the extent of the influence, posed by psychological

and societal factors, which have already been implicated by the literature reviewed in this chapter. Concerns about brain-stem death, uncertainty surrounding the criteria for donation suitability, and the infrequency with which organs and tissue donation presently occur, may all interfere with willingness to engage in dialogue with relatives at this emotionally sensitive time. The available literature related to these, and other psychosocial issues, will be reviewed in Chapter Two.



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## Chapter Two: Psychological And Societal Factors Influencing Organ And Tissue Donation

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### Chapter overview

**P**sychosocial issues related to donation behaviour have attracted a great deal of attention as scientists investigate factors that directly, or indirectly, influence the availability of human organs for transplantation. By far the majority of these studies have concentrated attention upon the general public and the factors influencing personal donation behaviour. Emerging from Chapter One are issues related to the behaviour of health professionals when involved in, or contemplating involvement in, the donation process.

In this chapter, the attention transfers to psychological and societal factors identified in the literature as affecting the responses, of health professionals, to the donation process. The issues of decision-making and donation behaviour will be discussed, so too will the literature related to health professionals' donation behaviour. Topics to be discussed include fears and concerns; costs and benefits; societal, and professional, issues related to death and dying.

The reviewed literature highlights the behavioural determinants that have been well researched, as well as those where there has been a dearth of scientific exploration. This information, together with that generated by Chapter One, will clarify the key issues to be explored in the present research, thereby justifying the focus of attention.

## Introduction

When transplantation was in its infancy, human behaviour and general responses, to the concept of donating organs after death, generated a plethora of research that has since been utilised to gain greater understanding of personal motives for donation. The effect of these on health professionals, and their influence on the supply of donor organs, motivated further research. It became apparent that explanations for professionals' donation related behaviour were complex and, although influenced to some degree by the organisational factors discussed earlier, such determinants were predominantly psychosocial in nature. These include concerns about the criteria used to determine brain death, fears relating to personal emotions and societal factors that appear to influence the way health professionals behave.

New et al. (1994) purported that health professionals must begin to consider their behaviour in relation to donor organs and tissue availability but did not make explicit how this should be achieved. There are few studies that have been designed to establish causality between health professionals' behaviour and donor organ supply. Rather the association has been inferred. An example of this arises in the study by Gore et al (1992) who found regional variations in tissue and organ donation figures. It was inferred that this observation could be attributed, in part, to health professionals' behaviour. Reviewing organisational aspects of donation enhances awareness of the influence that psychological and societal factors have, on behaviour, by highlighting some of the difficulties, experienced by health professionals, when confronted by this sensitive aspect of health care.

Therefore, in order to present a comprehensive picture of why it was both essential and timely for further research to take place, the key psychological and sociological concepts, appertaining to the donation related behaviour of health professionals, in the donation process will be expanded upon.

There is a dearth of research explaining why any health professional might choose to become involved in the donation process, and yet plenty of literature to provide professionals with sufficient justification for the subject to be avoided. Fears, misconceptions, as well as professional duty of care, and the desire to help others, appear to influence the decision-making process that takes place when health professionals contemplate participation in the donation process.

There are dangers associated with transferring the findings from one sample, or one culture, to another. Although researchers may have identified factors that can be attributed to pro-donation or anti-donation behaviour among the general population, one cannot assume that the same will apply to health professionals. The influence of professional socialisation, the development of attitudes and norms, specific to that society, may affect those acquired through general societal socialisation. Experiences, peer influence and other such factors can intervene to affect behavioural responses to the donation process (Wrobbel, 1989).

It is appropriate therefore, to begin with an overview of the conclusions generated by research, highlighting the roles and responsibilities that could, or should, be assigned to health professionals when operating within a voluntary system of donation.

## **Roles assigned to health professionals during the donation process**

When transplant programmes were in their infancy, researchers focused their attention on personal attitudes to donation among the general public. The implicit belief was that the individual held the key for the future of transplant surgery. Researchers such as Cleveland (1975a; 1975b), Cleveland and Johnson (1970), Claxton (1974), Corlett (1985) and Manninen and Evans (1985), surveyed members of the public to discover more about the possible relationship between

attitudes to donation and willingness to offer organs for transplantation after death. These contributions to the knowledge of donation behaviour enhanced understanding of the factors that motivate people to donate. They also identified fears and concerns, about donation and transplantation, which engender feelings of reluctance or disquiet about the process. Today, the findings remain of interest but have less relevance now that the potential donor rarely has the final say about donation. The family members and the health professionals have greater influence over the outcome of the donation process than the person from whom the organs or tissue might be retrieved, strange as that that might seem.

Some of the behaviours assigned to health professionals in relation to the donation process became apparent when the stages of the donation process were described, in Chapter One. These include applying the donor criteria to patients; carrying out tests to ascertain a diagnosis of death; breaking bad news to the patient's relatives; raising the issue of donation with them; formally requesting organs or tissue for donation; and liaison with the transplant co-ordinator to arrange the subsequent retrieval.

The studies that generated the above identified roles or behaviours sought out the views and opinions of medical staff, as well as nursing staff. There were methodological differences noted, particularly in sampling and the foci of the questioning when the research studies were examined. However, the combined contributions of the health professionals enhanced understanding of attitudes and knowledge of health professionals to donation and transplantation.

Prottas and Batten (1988) found that there was general agreement, among the ICU nurses and the neurosurgeons sampled, for personal approval of donation. The vast majority, almost 95%, commented that they would also consider donating organs from a family member. However, nurses did not perceive medical staff to be wholly supportive of organ donation. This raises the issue of peer support, and the influence that this perceived feeling of low support might have on co-operation or liaison between these groups. Surprisingly, medical staff were not asked to comment on the views of nurses. However, the perceptions of the nurses were revealing since nurses

work alongside medical colleagues, on matters such as organ donation. Prottas and Batten (1988 p.645) went further, to identify doctors as ‘the weakest link in the chain’ which needs strengthening. Whether this is done by developing medical staff’s skills, or by enhancing the parts played by nurses, is open to debate.

Other examples of research exploring health professionals’ behaviour related to the organ donation include a large-scale survey undertaken in Canada (Robinette et al., 1985) for the Canadian Ministry of Health; a smaller survey, of nearly 200 doctors and nurses, by medical staff from Cleveland, Ohio (Youngner et al., 1989); an early piece of research by Knutson (1968) a social scientist; and a more recent study, of UK origin, by Wakeford and Stepney (1989), who surveyed intensive care nurses and doctors, representatives from the medical professions and a large sample of the general population to identify obstacles to organ donation.

Wakeford and Stepney’s (1989) findings were generally supportive of those generated by Prottas and Batten, despite the geographical differences (Prottas and Batten’s study took place in the USA). They found that three factors emerged as possibly having a limiting effect on the process of donation: dislike of adding to relatives’ distress; lack of training in how to approach relatives; and adverse media publicity. Both groups of health professionals indicated these factors and, yet, it was the nurses who appeared most willing to want to do something about them. They specifically indicated the need to develop skills that would help them approach relatives. Wakeford and Stepney (1989) also found evidence, that was later corroborated by New et al. (1994), indicating that the incidence of organ retrieval increases if staff acknowledged some responsibility or professional duty for involvement in the donation process.

Certain issues relating to role assignment within the donation process are not contested, for example, the legal processes determining cause and certification of death, which require medical involvement. Other issues are less clear-cut and can lead to confusion about who should take on a particular role. One must consider personal feelings of the health professionals involved. If medical staff do find the

interaction with the relatives disconcerting, as suggested by Wakeford and Stepney (1989), roles should be allocated according to skill possession and ability. This might prevent the donation process being hindered by professional role demarcation. There is little evident to suggest, however the extent of influence of role demarcation in the UK.

The literature clearly indicates that certain roles should be assigned to nurses, and these will be discussed now.

### **Roles to be assigned to nurses during the donation process**

The empirical studies that contain data pertaining to the roles that would be best performed by the nurse are summarised in Table 2.1. They include: the identification or recognition of potential donors; talking to the family; making a formal request; emotional support of the donor's family; liaison and communication with other agencies involved in the donation process; and the care given to the potential donor. Information-giving, if not restricted to dialogue with the relatives, had noticeably less coverage and was less readily identified than the other roles (Houlihan, 1988). This was interesting, given the emphasis on the role of the nurse as an educator, as identified by Benner (1984).

No attempts were made, by the researchers, to claim exclusivity for these roles, but instead, it was purported that the nurse frequently assumes responsibility for them, albeit often with reservations. There are, currently, no standards or nationally agreed guidelines, in the UK, for those involved in the care of potential donors. Cultural traditions, personal motivation, and life experiences have all been implicated as factors that help to determine nurses' behaviour (Gibson, 1996).

Table 2.1: Nurses' roles in the Donation Process.

<i>Role</i>	<i>Authors</i>	<i>Country of origin</i>	<i>Methodology</i>
Identification of potential donor Referral of Potential donor to transplant co-ordinator Approaching the family Caring for the potential donor Supporting the family	Sophie et al (1983)	USA	Descriptive study to explore the cognitive and emotional aspects of the donation process using fieldwork, in-depth interviews and a self-report questionnaire
Identification of potential donors Approaching the family about organ donation Support for the family Liaison with transplant co-ordinator	Stark et al. (1984)	USA	Audit lasting one year in the ICUs of 8 hospitals to determine who recognised the donor as such, attitudes of family, nurses and doctors, and reasons why any donation did not take place. Combined with an educational intervention.
Identification of potential donor Referral of Potential donor to transplant co-ordinator Approaching the family for donation Caring for the potential donor Supporting the family	Matten (1988)	USA	Descriptive study measuring attitudes, knowledge and beliefs of nurses to organ donation using self-report questionnaire
Supporting the family Caring for the potential donor Potential donor identification Approaching the family for donation Supplying information to the family	Stoekle (1990)	USA	Descriptive study of nurses working in critical care areas of two hospitals, using self-report questionnaire to measure attitudes and knowledge of organ donation and transplantation

**Table 2.1 (cont.):  
Role**

<i>Role</i>	<i>Authors</i>	<i>Country of origin</i>	<i>Methodology</i>
Identification of potential donor Approaching the family for organ donation Caring for the potential donor Supporting the family Supplying information to the family	Coupe (1990; 1991)	UK	Interviews with relatives, nurses and doctors to explore their perceptions of the support and information given to the families of potential organ donors
Liaison with the transplant co-ordinator Identification of potential donors Caring for the potential donor Approaching the family about donation	Gaber et al (1990)	USA	Descriptive study of non-medical health professionals in critical care units of 27 hospitals. Used a self-report questionnaire to measure attitudes and knowledge of organ donation and transplantation.
Identification of potential donors Referral to transplant co-ordinator Caring for the potential donor Supporting the family Approaching the family for donation	McCoy (1994)	USA	Descriptive study of critical care nurses working in 1 hospital. Used a self-report questionnaire to assess attitudes and knowledge of donation and transplantation
Supplying information to family Caring for potential donor Supporting the family Approaching the family for donation Liaison with other professionals Supporting colleagues	Hibbert (1995)	Canada	Descriptive study involving semi-structured interviews with nurses in two neurological intensive care units.
Caring for the potential donor Supporting the family Post donation support for the family	Watkinson (1995)	UK	Descriptive study of critical care nurses working in four general and one neurological ICU. Used a self-report questionnaire to measure knowledge, attitudes and beliefs regarding the care of potential organ donors. Followed by semi-structured interviews.



Nurses, according to their Code of Conduct (UKCC, 1992a), are accountable for their actions, should act as a patient's advocate, and be autonomous practitioners. However, how far should nurses take this? The absence of standards allows the practitioner freedom to demonstrate professional judgement. However, the same freedom of judgement could heighten existing concerns, over roles, responsibilities and professional boundaries.

These dilemmas and role confusions appear to have stimulated a lot of the research into the role of the nurse in the donation process. As with many research questions, the issues have arisen from clinical practice. Many of the researchers in this area are, themselves, nurses working in critical care areas (e.g. Sophie et al., 1983; Coupe, 1990; Watkinson, 1995). The abundance of literature, not all research-based, indicates a desire to resolve these issues which cause nurses particular concern.

It is interesting to note that most of the studies, presented in Table 2.1, identified similar behaviours. This is significant given the differing origin of the studies. Few studies have emerged from the UK, with the majority emanating from the USA and Canada. The contribution to the body of knowledge on donation behaviour that has come from the North American studies cannot be ignored, since the UK studies appear to reach similar conclusions about attitudes and behaviour, thereby enhancing the credibility of earlier findings.

Generalising findings must always be performed with caution. In the case of organ donation research, there is a valid reason for not accepting, unconditionally, the conclusions inferred from American studies. One cannot assume that people in different countries will react in similar ways when exposed to the same phenomena until proven otherwise. It would be morally wrong to impose a system of donation, or any other health care practices, on a population just because studies in other countries have found that the people involved in the research reacted positively to such interventions.

Research needs to be carried out, using UK subjects, to enable the responses from the British population to be determined. Similar conclusions, to those of the American studies, might be reached. This would contribute to the generalisability of the research conclusions. If dissimilar findings emerge, however, areas of difference can be identified which would provide support for the original supposition that it is not safe to assume that people will react in the same way. The ideal solution, therefore, would be to collaborate with researchers in other countries and have multi-centre concurrent studies taking place.

Despite the plethora of studies relating to organ donation, and the findings from a recent study, by Sque (1996), that highlights the positive effect that interest in donation has on awareness and support for cadaveric organ donation among intensive care nurses, problems still exist. Sque expressed concern about variations in the level of support, for relatives, provided by nurses working in the general ward areas and in the Accident and Emergency departments of hospitals in the UK, compared with ICUs. She found that relatives, of the patients in the former areas, were not being offered the same opportunities and support, in relation to donation, that were so evident in the units, such as ICU, where donations occur more frequently.

Sque's work is, presently, unique, being the first large-scale exploration of donor families' experiences, in the UK. The variations uncovered, in nurses' understanding of the level of support and knowledge required by the relatives of potential donors, imply that raising awareness of donation issues has not, to date, been translated into widespread improvements in practice. By concentrating attention on the areas of the hospital where potential solid organ donors are traditionally most likely to occur, and promoting greater awareness of the donor card, the promoters of organ donation may, in the past, have paid too little attention to education and raising knowledge levels of nurses in areas other than ICU. If personal willingness to donate was all that was needed to encourage nurses to take on the roles identified in Table 2.1, this group of health professionals would no longer be identified as a barrier to increasing the supply

## **Rationalising and decision-making**

Baron (1994) talks about the process of rationalising that takes place when humans strive to make good decisions. However, for many people, beliefs particularly about death, dying and donation, appear to persist in an irrational way (Kent and Owens, 1995). An exploratory study found that some nurses reject corneal donation because they do not want their eyes destroying, and yet they intend their bodies to be cremated after death. Janis and Mann (1977) identified apparently irrational behaviour as coping mechanisms that help us deal with stressful situations. By avoiding, or ignoring, conflicting information, we reduce the anxiety that could be evoked through knowing that the decision made or the beliefs held are irrational and cannot be substantiated.

Donation decisions, therefore, made during a time of heightened emotions, were identified, in the literature, as being stressful and demanding for all concerned (Prottas and Batten, 1988; Sophie et al., 1983; Sque, 1996; Stark et al., 1984). These may not be quite so rational as Baron (1994) claims. By examining reality, rather than the ideal, the reasoning behind health professionals' behaviour may become more apparent. It is pertinent, therefore, to discuss the concerns expressed by health professionals in relation to the donation process.

## **Health professionals' concerns related to the donation process**

In the UK, concern about the influence of health professionals on the donation process became evident in 1970, following Crosby and Waters (1972) exploratory research. Key concerns related to lack of knowledge of donor criteria, lack of confidence in donor identification and reluctance to approach relatives because of fears of causing more distress. The authors suggested that

such feelings affected behaviour and contributed to the donation shortfall, a phenomenon that was apparent when kidney transplantation was in its infancy.

Despite the generally positive attitudes to cadaveric donation reported as prevailing among the health care teams caring for critically ill patients in intensive care units in the 1990s (Sque, 1996), the fears and concerns continue to affect health professionals' reactions to the donation process (Wakeford and Stepney, 1989).

The major fears or concerns about organ donation, and the donation process, that have been expressed by nurses and doctors are summarised in Table 2.2. These arise from individual research projects that have taken place, during a 16 year period, world-wide.

<b>Table 2.2: Health professionals' reservations about the Donation Process.</b>
Reservation about the validity of brain stem death criteria
Fear of adding to relatives distress
Knowledge of donor criteria
Unsure of the process
Fear of the reaction of relatives to a request
Fear of disfigurement
Lack of confidence in own ability to approach relatives
Timing of the request is wrong

Compiled from:

(Corlett, 1985; Cox, 1986; Diggs, 1986; Gore, Cable, and Holland, 1992; Grogan, 1979; Johnson, 1992; Kent and Owens, 1995; Kent, 1991; Kiernan, 1987; Malecki and Hoffman, 1987; Matten, 1988; Prottas and Batten, 1988; Robinette and Stiller, 1985; Robinette et al., 1985; Savaria and Swanson, 1995; Siminoff, Arnold, and Caplan, 1995; Soukup, 1991; Stark et al., 1984; Stoekle, 1990; Vernale and Packard, 1990; Wakeford and Stepney, 1989; Willis and Skelley, 1992).

The supporting evidence for these concepts will be contextualised now, beginning with expressed reservations about brain-stem death.

## **Reservations about brain-stem death**

Reservations about the concept of brain stem death, an essential prerequisite for solid organ donation as discussed in the previous chapter, appear to be widely expressed. Disagreement among the experts, on issues as fundamental as the determination of death, do little to ease anxieties of the generalist health professionals, who have less exposure to brain-stem death testing (Hannegan, 1987; Pallis, 1984; Rix, 1990). Poor knowledge of neuro-physiology could lead to uncertainty about the accuracy of the diagnostic criteria used to diagnose brain stem death, particularly when the cadaver has an appearance similar to that of a sleeping person. The concept of brain-stem death, or brain death as determined in the USA, calls into question traditional societal views of death, thereby creating an element of cognitive dissonance.

## **Lack of confidence**

Lack of confidence in personal ability to raise the subject of donation with the relatives is an issue that does not appear to be waning. Doubts were expressed about possession of interpersonal skills and knowledge, which deterred some nurses from participating in this stage of the donation process (Sque, 1996). As one intensive care nurse said “ We’re at the sharp end, meet me, teach us, support us - perhaps the yield will increase” (Sque, 1996 p.199). Such views imply that the present system of educating and informing nurses and doctors about donation and transplantation issues may not be having the desired effect. Lack of confidence also appears to be contributing to the persistence of the next fear to be addressed.

## **Increasing relatives' distress**

Reports of nurses' fear of increasing distress to relatives, by asking about donation, feature frequently in the literature related to Table 2.2. These persist despite contradictory evidence from studies of relatives' feelings surrounding the donation process (Pelletier, 1992; Pelletier, 1993; Sque, 1996). Nurses also expressed concern about the appropriateness of the timing of a donation request and subsequent reactions. The, often unexpected, news that there is no hope of recovery, may provoke a variety of reactions similar to those following bereavement, identified by Parkes (1986). Anger, disbelief, non-acceptance, are reactions that should be anticipated when bad news, of this magnitude, is broken to the patient's family members.

These misplaced concerns raise the issues of differing perceptions. O'Boyle (1996) has explored this concept whilst researching quality of life evaluation. He found that nurses' perceptions of a person's quality of life contrasted greatly with those of the individual, thus rendering subjective evaluations inaccurate. Unlike the evaluation tool, developed by O'Boyle (1994), to enhance the accuracy of quality of life evaluations, no objective forms of guidance can be found, in relation to the donation process. The only means of communication is the donor card, or donor register, at present, and, as was discussed in Chapter One, this is only minimally effective. Further investigation is indicated, to enhance understanding of the apparent intransigence of these misplaced beliefs.

## **Fear of disfigurement**

Fear of disfigurement appears to be an issue of concern for nurses. Nurses who have not experienced the act of retrieval of organs or tissue, or who have had an unsatisfactory experience, for example, when the donor was not treated with due respect, may believe that the process is disfiguring. To address this issue, the UK Transplant Co-ordinators' Association has developed standards for retrieval,

intended to eradicate poor professional practices. However, the literature indicates that disfigurement remains a genuine fear, particularly in relation to corneal donation. Both Kent (Kent and Owens, 1995; 1991) and Sque (1996) found that eyes are the part of the body that nurses have the greatest difficulty donating. Reason given by the nurses for this phenomenon include the effect that retrieval would have on personal identify (Kent and Owens, 1995). Removal of the eye was perceived as being disfiguring to the face.

Presently, there is no national strategy for educating health professionals about donation issues. Instead, regional transplant co-ordinators have the major responsibility for raising awareness, and providing educational support, among health professionals and members of the general public. The literature propose the inclusion of topics related to organ donation and transplantation in the pre-registration and post-registration curricula in the UK (Watkinson, 1995). However, there is no evidence to suggest that this has been acted on.

It is interesting to compare these reservations expressed by nurses, and other health professionals, with those of the general public.

## **Similarities in fears expressed by the public and health**

The fears of the general public closely resemble those of health professionals. A major survey of the general public in Canada (Robinette and Stiller, 1985; Robinette et al., 1985) identified six major reasons for not signing a donor card:

- concern about premature declaration of death
- fear of mutilation
- superstition and fatalism
- religious attitudes

- age
- no prior thought about donating.

These findings have been supported by later research in Holland (Hessing and Elffers, 1986), UK (Wakeford and Stepney, 1989) and Sweden (Sanner, 1994), and resemble those in Table 2.2.

Health professionals, who experience death more frequently than members of the public, should be more informed about death, dying and donation. However, death anxiety and fear of mutilation still feature as barriers to donation. Considering the plethora of papers, on death and donation issues, published by nursing and allied professional journals, it is disconcerting that the fears and misgivings are still apparent.

It is clear from the literature, including the Code of Professional Conduct (UKCC, 1992a), that nurses have a professional responsibility to become involved in the donation process. They have a duty of care to the families of potential donors to offer caring, compassionate and knowledgeable support. However, as Johnson (1992) indicates, nurses are genuinely concerned that they are inadequately prepared to help the families in an informed and professional manner. This supports Wakeford and Stepney's (1989) findings that lack of training in donation discussion placed some restrictions on organ donation in the ICU. If nurses cannot meet the families' needs, because of fears, misconceptions, lack of education or for some other reason, the cause of this failure should be addressed. The available literature provides possible explanations, which will be discussed now, beginning with the influence of socialisation.



## Socialisation

Nurses, together with other health professionals, have two societies to associate with and to fit into: the hospital and the outside world. The norms and the values, common to a society, are generally thought to be acquired, partially, through a process of learning that begins in childhood. Attributes acquired through general socialisation can assist us to understand where we fit into our society. Nurses have been exposed to the effects of this socialisation and, consequently, it can be assumed that they have adopted the attributes common to the outside world. However, nurses have also been exposed to another episode of socialisation, that of nursing. The traits common to the nursing society are acquired and exert an influence upon personal characteristics and behaviour. The similarity in expressed fears and misconceptions, about death and dying, of the nurses, and the general public (Bisnaire, 1988; Cacioppo and Gardner, 1993; Corlett, 1985; Coupe, 1990; Kent and Owens, 1995; Kolata, 1983) calls into question the primary determinant of attitudes and behaviour among nurses. General, rather than professional, socialisation may exert the greater influence, when nurses consider the donation process.

Despite the interest in exploring determinant of donation behaviour, there is little evidence to show that research has had any significant positive behavioural outcome, and produced any resultant changes to clinical practice. Sque's research (1996) reveals that fears, concerns, and misconceptions continue to influence nurses' donation-related behaviour. However, the extent of this influence remains unclear. Before nurses can effectively help to dissipate fears and anxieties among the lay population and colleagues, they need to be helped themselves. They have to recognise that their own feelings, though important, may be misplaced (see O'Boyle, 1994) and consequently, subjective judgements should not be the primary determinants of donation behaviour.

In a small scale, phenomenological, study Graham (1994) explored nurses' perceptions of how they perform their job. He paid particular attention to the

traits believed to be essential for the art of nursing. He found that nurses recognised the importance of being seen to provide a high standard of care to their patients. Implicit here is the influence of consonance with the wider societal view of the nurse and nursing behaviour. Graham also describes the influence of the professional society by revealing the desire for the nurse to be valued by their nursing and medical colleagues.

Strategies for dealing with the personal and societal influences on professional behaviour have to be developed by nurses (Kitson, 1993). Kitson argues that it is important for the nurse to become aware of these influences to practice before their impact can be overcome or minimised. The emotional cost of caring can, for some nurses, be high and may be overlooked or underestimated. Tschudin (1997) cites a message delivered by Christine Hancock, the General Secretary of the Royal College of Nursing, in 1994, who said that economy, effectiveness and efficiency were undermining knowledge, care and understanding in the UK's health service. Graham (1994) revealed that nurses feel undervalued whilst still expressing a desire to perform high quality care. Health care is changing and nurses have to adapt accordingly, to ensure that the caring and the high quality of care, so valued by the nurses in Graham's research, is maintained. Therefore, the impact of this emotional cost of caring, on behaviour, will now be discussed.

## **Cost-benefit analysis**

The literature emphasising the effect of participation in the organ donation process, on the psychological well-being of nurses, allies with the cost-benefit issues facing nursing. The emotional strain, that is placed on the nurse when engaged in dialogue with relatives, during the donation process, and nurses' behaviour, could be considered as key issues in a cost-benefit analysis (Bouressa and O'Mara, 1987; Coolican, 1987; Coupe, 1990; Degner, Gow, and Thompson, 1991; Field, 1993; Hart, 1986; Kiernan, 1987; McQuay, 1995; Robinette and Stiller, 1985; Satterthwaite, 1990; Sophie et al., 1983; Weber, 1985; Wolf, 1990).

There are many published papers illustrating this phenomenon. Sophie et al. (1983) discovered that the emotional strain, on the nurse, from caring for a potential donor and the family was often unexpected. This, however did not appear to deter nurses from engaging in such care in the future. Wolf's (1990) phenomenological study of nurses' post-mortem experiences included accounts of nurses who were caring for the cadaver after the retrieval. She concluded that their experiences were, in the main, emotionally draining but still seen as a worthwhile and necessary part of nursing.

These studies imply that the emotional costs, incurred when caring for these patients and their families, do not deter behaviour once the donation process has commenced. However, such costs may deter nurses from actually initiating the donation process. Consequently, the nurse may ignore or omit the possibility that the patient may be a potential donor. There is, at present, no research to support or exclude this proposition. The decision-making, undertaken when considering the donation process, appears to involve an element of risk-taking in addition to the cost-benefit analysis. The risk relates to the nurse's response to the emotional strain related to caring for the donor and family, and may influence future behaviour.

## Risk taking

Making practice-related decisions requires the individual to perform an analysis of the perceived outcome or consequence of any future action. As Payne et al. (1993) suggest, people draw on a number of different strategies to assist them in the solving of a problem, or deciding what action to take. The choice of strategy depends on the type of problem that must be addressed. Sometimes the choice is a conscious one whilst, at other times, we may be unaware of this evaluative process.

It seems that the decision-making process can force us to question the key factors

that underlie our choice of action. Payne et al. (1993) argue that we assess a potential outcome in terms of its being a 'good' decision, whilst at the same time assessing the degree of cognitive effort that is required. It may be that the person has to accept a compromise between accuracy and effort, which encompasses some degree of cost as well as benefit to that decision-maker.

In nursing, there are many situations where the effect of a particular action or decision cannot be predicted, yet a decision still has to be made. One such situation would be the breaking of bad news to either a patient or the relatives of a patient. Feeling inadequate to deal effectively with the situation, in addition to being concerned about the other person's reaction to the bad news, and uncertainty about one's role, can lead to avoidance, rather than participatory, behaviour (Lugton, 1994).

Decision-making strategies cannot be explained solely by personal psychological factors. The influence of societal factors must also be considered since nurses function as individuals, and as team players. Therefore, the effect that others have on a person's behaviour must be considered. The nurses, in Graham's (1994) study, acknowledged that peer pressure influenced their behaviour. The same thoughts have been reported in research that focused on nurses' attitudes to organ donation. Prottas and Batten (1988) revealed the perceptions of nurses towards medical staffs' support, or lack of, for organ donation and inferred that this has a deterrent effect, making nurses reluctant to raise the issue of donation with someone who may not hold similar views. Therefore, deciding to embark on any involvement in the donation process involves a risk analysis by the nurse. The nurse considers the possibility that a number of organs and tissue being donated for transplantation (a benefit) outweigh the possibility of a negative response by the medical staff when the issue of donation is raised (risk).

This raises a further, related, concept that interferes with the participation decision-making process, and which has been referred to as the 'bystander effect'. This relates to the behaviour of others and the effect that intervention, or non-intervention, may have on the nurse's subsequent behaviour.

## The bystander effect

Latané and Darley's (1993) pioneering work in bystander intervention has contributed greatly to our understanding of helping behaviour. The focus of this research was helping behaviour within the context of emergency situations. The bystander effect was noted following the stabbing of a woman in residential area of New York City. Despite the presence of a large number of onlookers, no assistance was given, even though the attacker is reported to have taken an hour to kill his victim. Hewstone et al. (1997) referred to this phenomenon as 'bystander apathy'. Latané and Darley (1993) suggested that this phenomenon could be triggered by diffusion of responsibility and social influence. The principles of this theory may help to explain why 'caring' professionals hesitate at the thought of becoming involved in actions that would help to realise a person's post-mortem wishes.

The basic premise, fundamental to Latané and colleagues' work, concerns the behaviour that occurs when one person is present, and those that occur when others are in the vicinity. When one person is the bystander, there is a feeling of personal responsibility for intervening, or providing assistance, in some way, which provokes an action response. However, when other bystanders are around, the level of responsibility for any intervention is shared. The bystander who may, if alone, have offered assistance, would, if others are around, take any cues for behaviour from the surrounding people. Inaction by others may result in group inactivity as happened in the case of the murder in new York City.

Latané and Rodin (1997) investigated the bystander effect further, by exploring the extent of intervention when people were faced with an emergency situation. The authors observed behaviour when the bystanders were complete strangers and compared the responses when the bystanders were friends. The findings reinforced Latané and Darley's (1993) earlier conclusions that non-intervention

was more common when with a stranger. However, when the bystander was known, the apparently limiting effect of inaction, caused by fear of embarrassment for misinterpreting the situation observed with the strangers, was overcome and assistance was more forthcoming (Latané and Rodin, 1997).

Applying the theory to the organ donation process, the situation could be one where, in an ICU, a nurse is looking after a severely brain injured elderly patient, who has just had the first set of brain stem death tests performed which indicated no cerebral activity. The nurse is aware that the patient's age excludes donation of most organs, except kidneys. The dilemma facing the nurse is similar to that facing the bystander in the emergency situation: does she wait for someone else to broach the subject of donation or should she intervene herself by suggesting the possibility and thus risk ridicule or embarrassment from her colleagues' unknown reactions?

Such situations are not emergencies, as defined by Latané and Darley, because they are not usually unforeseen or require immediate action. Nevertheless, organ and tissue donation situations are perceived, by those who have participated in the process, as being threatening, or harmful, to the person who decides to ask the relatives for their feelings about donation (Malecki and Hoffman, 1987; Matten, 1988; Wakeford and Stepney, 1989). The more recent work by Latané and Rodin (1997) proffer some hope when considering ways of encouraging staff to become more actively involved in the donation process. The familiarity of the nursing and medical staff, who provide care for patients in the ICU environment, should be exploited, if Latané and Rodin's propositions are considered. A more trusting ethos, where individual team members' opinions and actions are treated with respect, could limit the bystander non-intervention effect. Thus creating a safer environment, where nurses feel less inhibited in raising the issue of donor potential with medical and nursing colleagues, might enhance discussion behaviour, since the fear of humiliation is eased.

The next issue to be considered pertains to the apparent difference in the skills required to participate in the donation process, and those utilised when

participating in general nursing care. Therefore, the issues of societal norms and the care environment will be explored, beginning with societal views on death and dying.

## **Societal views on death and dying**

Nothing in life is more certain than death. No matter who we are, what we do, we cannot avoid the fact that we will die. Yet avoidance behaviour has been observed among health professionals when confronted by death and dying, most notably by Glaser and Strauss (1965), and Sudnow (1967). The majority of deaths, in western society, occur in hospital or in other institutions such as hospices or retirement homes. The care of the dying is not performed by family members, but by staff employed by the institution. Dying has, therefore, become isolated from 'normal', everyday, life and, as a result of this, many people in the UK reach adulthood or middle age without witnessing a natural death (Moscrop, 1995).

The reality of death, whenever it occurs, often comes as a shock. As Widgery (1993 p.17) emphasises, death is tidied away, through the use of floral tributes, funeral directors and a cremation or burial service. Furthermore, he comments that death is not, in general, the release that the media likes to portray. Rather it can be cruel, painful and, for some, demeaning. The isolation of the dying, and the haste to deal with death related issues such as arranging the funeral, has allowed a fear of death to develop in western society. This fear, for some, may provoke anxiety that is stressful and difficult to cope with. This death-related anxiety will be discussed further.

## Death anxiety

Death is a process over which we have no control, and we really do not know how we are going to deal with it until that moment of truth arrives. As Owens and Naylor (1989) identified, there are many worries and fears to be overcome. Panic, anxiety, fear of pain, fear of loss of dignity and a fear of loneliness are all issues that can heighten the emotional strain of the situation

Health professionals may also experience these fear and anxieties (Servaty, Krejchi, and Hayslip, 1996). Some death related attitudes have their origins in general socialisation and may develop prior to entering the medical or nursing professions. Others are formed as a result of experiences, education, and societal pressures exerted by colleagues and other health professionals. For many nurses and doctors, the first experience of death is feared and yet, when it happens, the reality is often far less disconcerting than expected. In general, the sight of a deceased's body is peaceful rather than frightening (Moscrop, 1995).

The first experience of a brain-stem dead patient may evoke similar fears. In reality, though, this too is not a fearsome sight because the patient looks asleep. However, it is this unexpected appearance that may dissonance. One expects a dead person to look 'dead'. The body should be cold to the touch, and have a very pale appearance that may be blue or grey in nature. The nurse or doctor, who has never experienced the brain stem death phenomenon before, is faced instead with a body that is warm to touch, with a pink, well-perfused appearance. The response to these incongruities, is cognitive confusion. Part of the brain is saying that this person has been diagnosed as brain stem dead and, therefore, is dead. However, another part of the brain is processing conflicting information. Visual cues indicate life, not death, thereby raising doubts about the accuracy of the diagnosis.

Parkes (1985) explains that those caring for the dying need to come to terms, where possible, with their own mortality as this will ease the difficulties of



providing support and dealing honestly with the patients and the relatives. Acceptance of death and dying, and understanding the dying process, are essential if the health professionals are to provide effective high quality care (Manley, 1986). Manley qualifies this by relating nursing responsibilities with the relatives' reactions to the bereavement. Nursing actions, especially those focusing on psychological support, can help to prepare the relatives for the death of the patient and facilitate the grieving process.

Nurses need assistance to help them to develop and refine the necessary skills to meet the relatives' needs. Those qualities can be cultivated through education and experience as well as reflecting on practice. Farrell (1989) argues that confidence in caring for the dying patient and family arises from experience not the artificial environment of the classroom. In nursing, learning by experience has great prominence. The use of reflection as a learning tool is favoured by many educators. Murphy (1994) highlights the value of reflective practice as a means of clarifying, and resolving, problems arising from practice. However, to gain the most from an experience, the knowledge base must be adequate, since this facilitates understanding.

Hurtig and Stewin (1990), in an experimental study, found that nurses with little personal, or professional, experience of death benefited more from an experiential approach to death education. Nurses who had experienced death, however, gained more from traditional didactic methods of education. The experiential approach, used in Hurtig and Stewin's work, tended to be more person-focused, using death awareness exercises, music and small group discussion to help the students to encounter the thought of death and promote personal death awareness. Brent et al. (1993) also found that a formal educational input, using death and dying coursework, had a significant impact on attitudes, with those nursing students who had a good knowledge base, together with experience of death and dying, having the more positive attitudes.

Despite the abundance of literature highlighting the negative aspects of caring for the dying patient and the family, nurses do get involved in this care and appear to obtain great satisfaction from performing last offices, and other post-mortem care. This may have evolved from the way society requires respect to be shown for the deceased.

## **Respect for the deceased**

The aim of post-mortem care is to remove any sign of suffering, soiling or tainting by death (Wolf, 1990). Nurses perceive post-mortem care to be the final act, the last thing that they can do for a patient. Manley (1986), drawing on her professional experience of caring for dying patients, suggests another reason for nurses' participating in this care. She comments that the act of laying-out the dead person has additional meaning for the nurse, because it gives the opportunity for her to work through her own feelings about the death, whilst ensuring that the body is treated with dignity and respect.

The desire to respect the body of the deceased, whilst still meeting the deceased's wishes, may cause conflict when deciding what action to take concerning donation request. The majority of the research, that has explored relatives' needs at this time, overwhelmingly agrees that issues relating to organ or tissue donation should be discussed, since this offers an opportunity to respect the patient's wishes (Bartucci and Bishop, 1987; Bisnaire, 1988; Cacioppo and Gardner, 1993; Coolican, 1987; Corlett, 1985; Coupe, 1991; Doering, 1996; Hart, 1986; Horton and Horton, 1990; Malecki, 1987; Pelletier, 1992; Pelletier, 1993; Savaria, Rovelli, and Schweizer, 1990; Sque, 1996; Vernale, 1991; Willis and Skelley, 1992).

Harris et al. (1991) suggest that where the deceased's wishes are stated, these should take precedence over the next-of-kin's wishes. However, they also found, using an experiment design, that if the potential donor's wishes are not made

explicit, the picture presented is less straightforward. The decision-makers tried to make inferences of intention using religious beliefs, age and other knowledge of the deceased, all of which may lead the decision-maker to reach the incorrect conclusion. As was demonstrated by O'Boyle (1996), personal attitudes and beliefs can colour the objectivity of the decision-making process.

There are concerns, however, that the act of organ retrieval may be perceived as disrespectful to the dead body (Foy, 1990). The altruistic, helping, feelings triggered by thoughts related to the giving of organs for transplantation can conflict with the set of emotions that are evoked at the thought of the retrieval, or the removal, of those organs from the dead person (Youngner, 1990). As a society we appear to be sensitive to the treatment of dead bodies. The beneficial reasons justifying the use of human parts are counterbalanced by any feelings of distaste or discomfort, evoked when one considers the defilement or mutilation that is perceived to occur when the organs or tissue are removed. Youngner (1990) referred to these fears as 'the dark side of organ transplantation', and argues that they impose obstacles to progress in organ donation and transplantation. These may deter health professionals from advancing the donation process, thereby denying the relatives the opportunity to deliberate on such issues.

The factors that have been shown to affect donation behaviour must be placed in context with wider issues related to behavioural influences. The barriers and motivators for donation involvement are, to a large extent, individual in that some people will be adversely affected by issues like fear of mutilation, whilst other nurses can rationalise more clearly and are willing to participate in the donation process.

Death is a personal process and can be a lonely one, particularly when it occurs in hospital. Whereas, in the past, the dying person would be surrounded by family and friends, in the familiar location of home, this is now less common. The routine of the hospital setting is not conducive to the social events of death

and dying. The distinction between home and hospital is even starker, when death occurs in an ICU. Here the person is surrounded by technology aimed at saving life, rather than supporting the dying. The impact of this environment on caring for the dying will be reviewed now.

## **Caring for the dying in critical care units**

Youll (1989), an intensive care specialist nurse, reviewed medical and nursing staff's understanding of death and dying in an ICU and concluded that many of his colleagues felt that their knowledge of death was very limited. They also expressed emotional difficulties when caring for the dying, particularly the younger patients. Such conclusions are notable, considering that ICUs are recognised as places where death is common, due to the severity of the patient's condition. Youll, however, went further, to speak of conflicts evident from behaviour when nurses are confronted with death. These will be discussed now.

## **Conflict arising from the aim of admission to an ICU**

The aim of admission to an ICU is to cure and facilitate recovery. When this does not occur, psychological and professional conflicts can arise. The environment and organisation of the ICU do not assist resolution of conflict, in that they contribute to making the ICU a less than satisfactory location for the psychospiritual aspects of care required during the dying process. Space and privacy is limited by the design of the ICU. Patients are often nursed in close proximity, with screens or curtains separating one from another. The limited space around the bedside, combined with limited facilities for relatives, when away from the patient, result in visiting restrictions being imposed, allowing close family members only.

Caring for the dying in the ICU environment may evoke feelings of failure and helplessness among health professionals, which can adversely affect behaviour. Consequentially, avoidance of the dying patient or the relatives, first mentioned by Glaser and Strauss (1965), may occur. This can lead to lack of empathy, reduced personal interaction and involvement with the patient and the relatives, at a time when the need for psychological support is great (Thompson, 1994).

Reactions, of health professionals, to death may vary according to the amount of time, and preparation, that the staff and relatives have to adjust and come to terms with the hopelessness of the situation (Eastham, 1990). For some nurses, feelings of loss are greater when the nurse has had time to become personally involved with the patient and the family patient. When death occurs, the nurse will experience bereavement in a similar way as the relatives. Coping with the needs of the grieving relatives is made more difficult when the nurse is trying to deal with her own emotions.

Becoming personally involved with the patient, and relatives, does not appear to be detrimental to care. This is particularly evident in areas such as coronary care (CCU) where the nature of the treatment provides a greater opportunity for communication with the patients than in the ICU (Field, 1989). Nurses, working on a CCU in England, suggested that the personal involvement with the patients and their families had a positive effect on nurses' behaviour. Field summarised that, in a setting where the majority of the nursing work is of a specialised and technical nature, caring for the dying patient provides an opportunity for nurses to carry out other, more fundamental, nursing skills, which enhance the quality of care for the recipient of these action (Field, 1989 p.87).

Not all nursing interactions are so positive. Thompson (1994), observed that some health professionals, involved in the care of the dying, showed a lack of empathy and caring. This contrasts with the humanistic approach to care that is now advocated by the nursing profession. Thompson (1994) commented that a personal hope for the future was that the care of dying patients should involve

compassion, love, communication and connection, all features of the humanistic approach.

## Importance of caring in the ICU

Brykczynska (1997a) suggests that caring in nursing arises from the duty of care principle, and then develops to reflect the desire for humanity that complements the caring duty. Caring has been cited as one of the key distinguishing features of nursing. However, this view has its advocates and critics. It is an issue that has been debated for many years, as far back as Nightingale in the last century, and it seems that discussions will continue until nursing can more clearly define itself.

Definitions of caring vary among the nursing theorists, reflecting the different philosophical stances. Nevertheless, it is becoming generally accepted that nurses have a caring role, which requires personal involvement to assist the clients and relatives for whom the nurse is responsible (Clifford, 1995). Without the humanistic perspective of caring, nursing becomes a series of tasks. Brykczynska commented that the job of nursing is to promote the ideology of caring, when support is low, and to discover new ways of caring when old methods of nursing are seen to be not working.<sup>1</sup> Attention needs to be paid to the value of caring when considering the needs of the dying, and apply recommendations to the care of the potential organ donor and the grieving relatives.

Bush and Barr (1997) identified the potential benefits that caring can bring to the nursing staff, in the form of personal fulfilment and satisfaction, new knowledge and greater recognition. These and other issues will be discussed next.

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<sup>1</sup> For further reading please refer to G. Brykczynska (1997) *Caring - the compassion and wisdom of nursing*. London: Arnold.

## Factors that encourage nurse participation in the donation process

Caring may be a reason for becoming involved in the donation process. For nurses, caring for the dying patient is, quite simply, part of the nurse's normal work when providing professional humanistic care. The nurse may not feel completely comfortable with all aspects of care, but still participates because it is important, for the nurse, to meet the needs of that particular patient and family. Nursing the patient and the family involves more than physical actions. It also encompasses caring for the psycho-social dimensions of the person. To do this effectively it is important that sufficient information is obtained to enable the nurse to 'know' the patient; and to understand that person's particular needs be they physical, psychological, social or spiritual (Heslop and Oates, 1995). As Hudak (1994 p.48-9) reiterated, when discussing the nurse-patient bond that develops within the intensive care unit, the result of a close working, caring relationship is "the caring, trust and support, developed between the nurse and the patient, which constitutes the foundation of that bond. No other health professional has the consistent and frequent opportunities to interact with the patient within this same framework. No other framework of interaction can offer the patient a more powerful source of support: a professional, knowledgeable, foundation and a caring, human acceptance as a person of worth and dignity."

There is little evidence in the literature to explain why nurses get involved in the donation process. Weber (1985) suggests that rewards encourage participation in the nursing care of the potential donor which outweigh, or offset, any difficulties. Rewards are individual and personal, but they may include satisfaction felt when the nurse has provided the highest standard of care, or the fulfilment experienced when the nurse is sure that the relatives were able to make the decision that was right for them at that time.

Watkinson (1995) explored the perceptions and experiences of critical care nurses arising from the care of potential and actual organ donors. She found that rewards from experience were not the key for motivating involvement. Four, of the eight nurses involved in the interviews, commented on the dynamism of the work, which encouraged involvement by making them feel good. The drain on emotions from this dynamic experience could be viewed as a necessary evil, without which the nurses might not perceive that they had worked hard, or provided such a high level of psychological and physical support, for relatives and peers, during this difficult time.

As a consequence of the high nurse to patient ratio, that is the norm in UK intensive care units, the nurse is able to develop a close affinity with the patient and the relatives. The nurse who cares for the patient is the person who, for the duration of the span of duty, should identify the patient's individual physical, psychosocial and spiritual needs, and deliver all the necessary interventions to meet these needs. Arising from this relationship, between the nurse and the family members, comes mutual trust, rapport and support, particularly during emotionally charged situations (Burnard, 1981; Clifford, 1986; Coupe, 1990; Evans, 1995; Farrell, 1989; Field, 1989; Field, 1993; Franklin, Crombie, and Nicholls, 1996; Gibson, 1995; Johnson, 1992; Owens and Naylor, 1989; Pilsworth, 1994; Sque, 1996; Townsend, 1995; Watkinson, 1995; Wright, 1988; Youll, 1989). This satisfaction of meeting needs, and being needed may, therefore, be a rationale for involvement in the donation process.

However, a note of caution must be introduced here. Taking on a role because it is part of your job can lead to the development of potential problems, such as stress and burnout, arising from dissonance, low self-confidence, and feelings of lack of support (Krekeler, 1987). Nurses need to be helped to identify the issues that are creating dissonance so that they can adapt positively, to resolve the conflict. Their actions, or the decisions that they make, become focused on reconciling that psychological conflict.



## Dissonance and nurses' donation behaviour

To understand the feelings of dissonance more fully one has to begin with the views, expressed by Leon Festinger, who proposed one of the first models to conceptualise the behavioural effects of experiencing feelings, or situations, that are out of fit with personal or societal norms. Festinger called these psychological responses 'cognitive dissonance'.

Festinger's basic assumption is that incompatibility with any two cognitive elements such as knowledge, views or beliefs, creates tension and drives the individual to act in such a way as to reduce the amount of conflict thus easing the dissonance being experienced (Brigham, 1991). Cognitive dissonance theory explains how attitudes can affect behaviour when two cognitive elements are at odds (Festinger, 1962). Therefore, dissonance motivates the person to strive for harmony or consonance. Festinger's theory, espousing the concept of self consistency, has, according to Glassman (1989), stimulated a great deal of research in the field of social psychology.

There are some critics of the theory, however, and new, more applicable theories have emerged from Festinger's original work. Cooper and Fazio (1984) are two psychologists who have taken a new look at the dissonance theory. They proposed that the dissonance effect only occurs under certain conditions. These include the choice to engage in behaviour that will counter the prevailing attitudes; commitment on the part of the individual to this behaviour; the possible outcome of unchanged behaviour that might be unpleasant; and a feeling of personal responsibility for any behavioural outcomes.

Baron (1994) suggests that other factors work with dissonance reduction to help individuals reconcile their internal differences, one of which maybe intuition. A degree of rationalising takes place, as the individual convinces themselves that the action is the correct one given the particular circumstances. It may be that

people change their behaviour because they feel that they have made a good decision to do so. Baron's ideas support those of Cooper (1971) who concluded, from experiments about decision-making, that being able to foresee the outcome of an action increased the effect of decisions made in the past. People, therefore, try to justify their decision to take a certain course of action. Baron felt that people do not like to think of themselves in bad light, such as bad decision-makers who ignore the relevance of truths, and so they adjust their own beliefs, to convince themselves that these are the true beliefs. The behaviour that might arise from such decision-making may be avoidance.

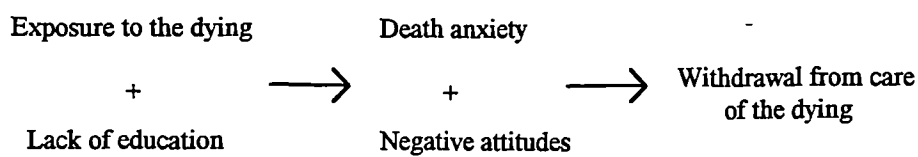
## **Avoidance as a coping mechanism**

Quint identified possible reasons why nurses are reluctant to participate in an unfamiliar, or potentially threatening, situation. She saw dying as a socially structured phenomenon and carried out research to understand the reactions of the staff, and the social interactions that took place, in relation to the dying process (Quint, 1967; Quint, 1966).

The actions of the nurse centred on coping strategies to protect composure and maintain the general running of the ward. Quint found that nurses tended to protect themselves from situations, or interactions, that might affect them emotionally or cause them to not appear as so professional in their work. Various situations arose when Quint observed more avoidance tactics at work. Generally these involved patients whose death was an extraordinary loss, socially, such as the loss of a child, or when a lot of contact was required with patient, and the family, and the nurse became personally involved. Unexpected death created a major threat to the nurse's composure and feelings of guilt were greatest at this time. The nurse was likely to take the death personally and, consequently, felt responsible for the situation. The greater the degree of personal involvement with such patients prior to death, the greater the distress felt by the nurse.

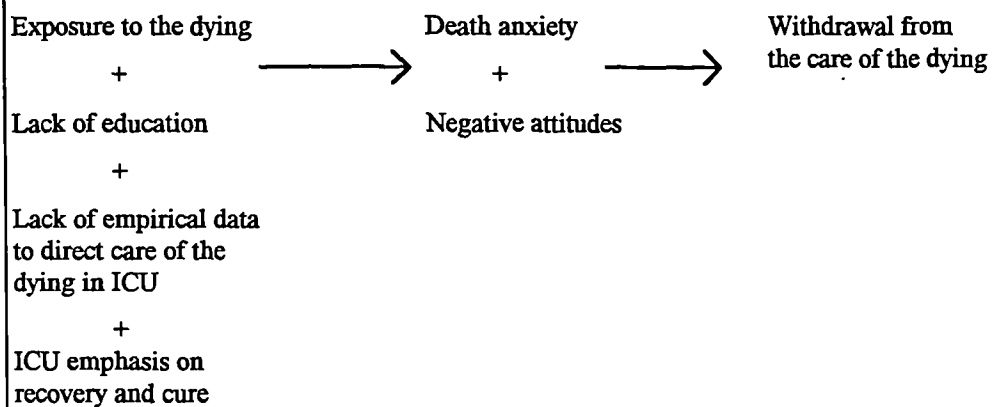
The avoidance behaviour observed by Quint (1966) is still recognised in present day nursing, as indicated by McClement and Degner (1995). Quint (1966) devised a theoretical model to illustrate the observed relationships between involvement and death awareness. This has since been modified following research that focused on the actions of nurses caring for the dying in the intensive care unit (McClement and Degner, 1995). Both versions are shown below in figures 2.1 and 2.2.

**Figure 2.1: Quint's model of caring for the dying**



(from McClement & Degner, 1995, page 409)

McClement found that Quint's model did not address all of the issues currently facing nurses caring for patient who die in the intensive care environment. McClement also wanted to include in the equation, the dearth of research offering guidance in relation to the direct care of the dying in the ICU, and the influence that the ICU recovery and cure emphasis may have on the interaction behaviour with the dying. She proposed that these should be considered when one is contemplating their combined effect upon death anxiety and the formation, or reinforcing, of negative attitudes towards death and the dying. The consequence, according to McClement, of all of these is to deter nurses' active involvement with the dying patient (see Figure 2.2).

**Figure 2.2: McClement's revised model of caring for the dying in ICU**

(from McClement & Degner, 1995, page 409)

McClement and Degner (1995) emphasise the importance of research, carried out in clinical areas, to understand nurses' reactions to caring for potential organ donors and the donation process. These authors argue that nurses must reflect on their practice and identify the shortcomings in their care of the dying, thereby enabling behaviour, considered to be essential for high quality care, to be clearly identified.

Lange (1992 p.26) a critical care nursing specialist in the USA, proposed that "nurses are in the best position to have a positive effect on organ and tissue donation because they have a close relationship with the family and are prepared to educationally and often experientially to provide compassionate support."

This view, however, puts pressure upon the nurse who may be experiencing similar psychological responses, to the death of the patient, as those experienced by the relatives. Hibbert (1995) identified this, and other stressors experienced by nurses during a small exploratory study (see Table 2.3). These will be used to clarify the information emerging from the literature, presented in this, and the previous, chapter.

**Table 2.3: Stressors experienced by nurses caring for organ donors and their families**

<p><b>Anticipation Stage</b>          Threat to life          Information and supportive needs of family members          Physician's hesitancy to intervene</p> <p><b>Confrontation stage</b>          Informing families about diagnosis of brain death          Inconsistent commitment of physicians to organ donation          Approaching families about organ donation</p> <p><b>Maintaining donor</b>          Waiting for retrieval</p> <p><b>Postconfrontation stage</b>          Returning to an empty space</p>
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## The stressors: the picture so far

There are many issues such as costs, risks, lack of knowledge, lack of skill and experience, that have been proposed as deterring further involvement in the donation process, other than providing general nursing care for the potential organ donor. Despite this, research shows that nurses do participate in some very sensitive and emotionally difficult aspects of the donation process as identified in the studies summarised in Table 2.1.

Concern about the threat to life and the informational needs, addressed by McClement's model of avoidance behaviour, can be supported by a number of other studies such as Sophie et al. (1984) and Wakeford and Stepney (1990). The perceived hesitancy by physicians to intervene and identify a person as being potential donor clearly adds another dimension to McClement's model. It calls into question the extent of team-working and collaboration that really takes place in critical care areas, if the reluctance of one section of the team can cause the donation process to halt.

Prottas (1994) concluded, from his extensive research of health professionals and organ donation behaviour, that it is the interpersonal aspects of the donation process that daunt medical staff, rather than the more technical aspects such as

the diagnosing of brain-stem death. He found that nurses are more willing to interact with the relatives of the potential donor and less likely than medical staff to anticipate adverse behavioural reactions by the family members. Field (1998) called nurses work 'all-encompassing' in comparison with doctors, reflecting the amount of patient contact time that a doctor's workload allows. The doctor has far less opportunity to develop a close, trusting rapport with the relatives in the same time-span than the nurse. As Heyse-Moore points out (1995) nurses are constantly on the ward working closely with the patient and the family. They can use their interpersonal and communication skills, such as empathy, and the ability to listen effectively to enhance the quality of care.

The confrontation stage relates to that in the donation process when health professionals break the news of the poor prognosis and later the death of the patient to the relatives. Again the behaviour of the medical staff is identified as causing anxiety to the nurses. The inconsistent nature of that behaviour can make actions, in future situations, unpredictable. There is evidence, here, of the bystander effect, which suggests that an element of risk maybe perceived by the nurses. If the doctors consistently refuse to intervene, then the nurses know what to expect. However, any inconsistency may make a decision, related to participatory behaviour, very difficult to reach.

The maintenance of the donor and the wait for the retrieval, although identified by Hibbert as being stressors, may also be factors that encourage participation behaviour. The feelings of satisfaction derived from providing holistic care in the ICU setting, may be emotionally draining, but also rewarding.

The presence of an empty bed, previously occupied by the organ donor, serves as a reminder of what has just taken place. This reminder may reinforce feelings of failure that the recovery and cure ethos in the ICU has not been achieved, and that death has occurred.

There is little, or no, evidence in the available literature to clarify the effect of experience on level of confidence in one's ability to deal effectively with the stressors identified by Hibbert (1995). Bad experiences were identified as factors that contributed to avoidance or withdrawal behaviour, by Quint (1966) and, later, by McClement and Degner (1995). Servaty et al. (1996) suggested that experience of death, whether it be drawn from real-life events, or from professional training, appears to be the crucial factor in lowering levels of apprehension, particularly in the area of interacting with relatives. There is no evidence, in the UK, to support or discount such views.

Professional experience and education, however, cannot account for all the variations in behaviour that have been observed in the studies of caring for the dying. Similarly, willingness to become involved in the donation process cannot be attributed to professional experience alone. The decision to become more involved in the stages of the donation process that might require some risk-taking, and engender some emotional costs to the nurse, is complex. Despite all of the studies that have been carried out, to date, there is still much that is not understood about the factors that influence such behaviour. Attitudes, beliefs, social norms, professional obligations, and to a greater or less extent, rationality, all interact until a decision is reached. Future behaviour is notoriously difficult to predict, particularly when many variables can, apparently, intervene to create conflict, self-doubt, or subconscious reluctance.

The pioneering work by Quint (1966), followed by the work of McClement and Degner (1995), served to conceptualise the behaviour involved in the care of the dying and the factors that result in avoidance, or withdrawal from this aspect of health care. There is not, at present, a similar model that clarifies the issues discussed here, which relate to the care of dying patients who might become organ or tissue donors. The aim of this research is to do just that: add to the body of knowledge related to donation behaviour by exploring the relationships between attitudes, knowledge and behaviour, taking into account societal norms

and irrationality. The aim is to engender clearer understanding of the issues that appear to influence nurses' involvement in the donation process.

## Chapter summary

In this chapter, the literature identifying the factors that may influence the supply of donated organs and tissue for transplantation has been reviewed.

Psychological, societal and professional issues have been explored in order to contextualise the focus of this thesis.

Giving cause for concern, at the present time, is the apparent reluctance of health professionals in the UK, to raise the subject of donation when the appropriate time arrives (New et al., 1994). Researchers have, for a number of years, implied that such behaviour obstructs the supply of donor organs and tissue for transplantation and contributes to the increasing waiting list figures (Corlett, 1985; DeChesser, 1986; Foy, 1990; Gibson, 1995; Gore, Cable, and Holland, 1992; Wakeford and Stepney, 1989).

Explanations for this apparent reluctance to participate in the donation process have been proffered. Prottas and Batten (1988) commented that the act of requesting organs is one that is without compensation, and is draining in terms of time and emotions. Others argue that cognitive dissonance, evoked by the concept of brain death, may cause conflict among health professionals caring for the potential donor (Corlett, 1985; Coupe, 1990; DeChesser, 1986; Field, 1993; Hibbert, 1995; Malecki and Hoffman, 1987; Sque, 1996; Wakeford and Stepney, 1989; Watkinson, 1995; Willis and Skelley, 1992). This may be due, in part, to inexperience, lack of knowledge, personal attitudes, beliefs and societal values. These appear to influence the decisions made in relation to the care that is given to the patient or the family during this time of crisis (Sophie et al., 1983; Sque, 1996; Stark et al., 1984).



Roles related to the donation process have been identified that may be best suited to the nurse (see Table 2.1). Nurses' involvement in the donation process is a practice-related issue that requires further investigation, not least because transplantation of human parts continues to expand at a rapid rate. At some point during the life cycle, the individual's post mortem wishes need to be identified if those wishes are to be fulfilled. The literature proposes that nurses are ideally placed to do this. However, a word of caution must be conveyed at this point. Nurses do not automatically acquire interpersonal skills and caring attributes. Also, the possession of such skills and using them effectively may be different issues.

There are many variables that appear to affect donation participation decision-making. The law related to donation is unlikely to be altered in the foreseeable future. Therefore, it is pertinent that the factors that directly affect nurses in the UK are identified and their impact on nurses' behaviour explored. The rationale for the research will be discussed further in the next chapter.

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## Chapter Three: Rationale and Research Statement

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### Chapter overview

**T**he contents of this chapter derive from the discussion of the reviewed literature, which, together with my own professional insight, provide the justification for further research. The rationale behind the present research project, the aims and objectives, and the relationship between these, and the selected theoretical framework, are all discussed. This information will complement the literature review and provide justification for the methodology, presented in Chapter Four.

## Rationale for the research

The concepts to be studied, and the justification for the research project, have been derived, partly, from the comprehensive review of the available literature, focusing on, and related to, donation and transplantation. The large volume of information, predominantly from North American researchers, enabled potential key issues, related to nurses' role in the donation process, to be isolated. However, the part played by clinical practice, in raising awareness of the apparent consequences of health professionals' inactivity in the donation process, must also be acknowledged.

Whilst practising as a nurse, in the intensive care environment, the discrepancies in donor recognition, identified by Gore et al. (1992), became apparent. Patients were rarely assessed for tissue donor potential even though asystolic deaths frequently occurred. This phenomenon contrasted strongly with that of assessment for organ donor potential undertaken on those patients whose deaths could be directly attributed to brain stem injury, and where the heart remained beating despite a state of death being declared. These were few in number, by comparison, and yet the donor potential was almost always recognised and acted upon by the health professionals.

Professional curiosity about the causality of the apparent low incidence of tissue donor identification, within the ICU setting, resulted in an earlier, small-scale study, carried out in 1991 (Kent & Owens, 1995), in which nurses' attitudes to organ donation were explored. The findings implicated personal attitudes as contributing to the non-identification of potential tissue donors. This was later corroborated by Sque (1996). The concept of avoidance, due to personal inhibitions, as being a factor that might adversely affect nurses' involvement in the donor identification and discussion stages of the donation process, emerged. The influence of attitudinal factors, particularly personal feelings towards donation and transplantation, became an issue for further research.

Of particular interest was the influence that attitudinal factors may have on nurses' personal perceptions of ability to participate in, what have been identified as, difficult and sensitive phases of the donation process. Difficult because there may be conflicting feelings experienced by the nurse, particularly at the thought of talking about death and the retrieval of body parts after death. Sensitive because research has associated the quality of interpersonal skills with the outcome of any donation inquiry (Coupe, 1990; Perkins, 1987; Savaria, Rovelli, and Schweizer, 1990).

An issue that is central to the current investigation, is the right of an individual to decide about, and to express, personal wishes relating to post-mortem intentions. Any behaviour, by nurses, that has the effect of denying that right contravenes the UKCC's Code of Conduct (UKCC, 1992a). Furthermore, the NHS in Wales strives for 'A People Centred Service' (Welsh Office, 1989) which requires professionals, within the NHS, to respond sensitively to individual needs by being responsive and offering informed choice. Therefore, there is an implicit requirement for nurses to reflect on their practice and adapt to meet the changing needs of patients, now and in the future.

The reviewed literature highlighted the roles that have been associated with nurses, or assigned to nurses. However, there is a dearth of research exploring nurses' responses to those roles. There is no legal requirement to formally discuss donation with patients, however, as indicated by the statement from the Welsh Office, nurses have a duty of care to ensure that they respond to wishes or needs.

Unfortunately, it appears that the prospect of participating in the discussion of donation intentions is perceived as stressful, as identified by Canadian research (Hibbert 1995). Therefore, it is pertinent for the factors influencing nurses' participation, in the donor identification, and donation discussion stages of the donation process, to be explored further, in the UK. The research focus has been

contextualised by the literature, and by clinical practice. A statement setting out the main issues to be investigated will now be presented.

## **Statement of the research problem**

Evidence from research and practice suggests that nurses in the UK have misgivings about the possible roles within the donor identification and the donation request stages of the donation process. The purpose of this research is, therefore, to determine if nurses, in the UK, feel willing, and able, to participate in the donation process. The research process will focus on the relationship between psychosocial factors and perceived ability to undertake donation-related professional behaviour. The phases of the donation process that are of particular interest are donor identification and donation discussion with relatives of the potential donor. Responses from present day and future nurses will be examined.

## **Aims of the research**

The aims of the research are as follows:

- To discover if nurses feel able to actively participate in the discussion of post-mortem organ and tissue donation wishes with either the patients at some time prior to their death, or with relatives upon the patient's death.
- To compare the findings from one health region in North Wales with one English region, to discover if any regional variations significantly correlate with perceived ability to discuss donation.
- To explore the apparent concept of nurses' avoidance of post-mortem wishes in the acute hospital setting.

- To identify the needs of nurses, who are caring for potential cadaveric donors, and recommend mechanisms for incorporating any suggestions, relating to support structures, into practice.
- To evaluate the effect of higher education on pre-registration student nurses' attitudes and knowledge towards organ and tissue donation and transplantation, and to compare the results of pre-registration student nurses, at varying stages of training, with those of qualified nurses.

To achieve these aims, a series of objectives were identified. These objectives directed the research design and general methodological issues, which will be discussed in more detail later.

## Research objectives

These objectives form the central tenets of the research, and clarify the foci of the investigation. In view of the complexity of the human behaviour, the research was divided into three distinct, but related studies. Some of the objectives relate to just one study, whilst others are explored, in different ways, in two or all of the studies, to achieve the research aims:

- To assess the extent of influence posed by personal positive attitudes, on self-perception of ability to discuss donation
- To assess the extent of influence posed by personal negative attitudes on self-perception of ability to discuss donation
- To assess the extent of influence posed by comprehension of the donation process on self-perception of ability to discuss donation
- To assess the extent of influence posed by professional factors, such as area of work, clinical grade, and professional qualifications, on self-perception of ability to discuss donation

- To determine the frequency of routine assessment of deceased patients' potential for organ or tissue donation

These emerged, predominantly, from the existing body of knowledge and the associated variables have been specified by the research problem. The above issues will be explored, quantitatively, during Study One, using the following independent variables to increase understanding of nurses' donation behaviour:

### **Independent variables for Study One**

Age

Sex

Religious affiliation

Post mortem disposal intentions

Professional qualifications

Clinical grade

Clinical area of work

Personal positive attitudes to organ donation and transplantation

Personal negative attitudes to donation and transplantation

Personal commitment to donate organs

Personal commitment to donate tissue

Previous experience of organ/tissue donation

Previous experience of transplantation

Personal knowledge of the donation process

The dependent variable, for Study One, will now be discussed.

### **Dependent variable for Study One**

The dependent variable is, according to Grimm (1993), the variable that measures the influence of the independent variable. Grimm also advises that the dependent variable should reflect a specific, clearly defined, behavioural response. One of the objectives in Study One is to determine if respondents believed that nurses should be undertaking donation discussions with relatives.

The second is to explore the factors that influence such behaviour. Two questions contained within the Organ Donation Attitude and Knowledge questionnaire address these issues (see Appendix 7, question numbers 30 and 31). The development and design details relevant to the questionnaire will be discussed in Chapter Four. Nonetheless, it is pertinent, here, to expand upon the rationale for choosing Question 30 as the dependent variable for Study One. This measures personal perceptions of ability to raise the subject of donation with patients/relatives.

Question 30 requires respondents to evaluate their perceptions of ability to approach a potential donor family and discuss donation through the use of a simple 'yes/no' categorical response. Opportunity for expanding on, or clarification of, the rationale for this decision are provided.

Christensen (1988) specifies the decisions that need to be taken when determining the dependent variable, which must be sensitive to the influence exerted by the independent variable. Firstly, he suggests that the researcher identifies a specific measure, in this case, Question 30. Other issues to be considered include the motivation of the respondents, to take participation in the study seriously; and the extent to which the respondent is answering the question truthfully. To assist in this process, Christensen argues that the more commitment that is demanded of the respondent by the dependent variable, the greater the degree of confidence in the results. Question 30 requires a categorical response, to direct respondents to make a narrow choice. If a rating scale had been used, the greater number of choices, available for respondents, could have increased the likelihood of error.

The reliability, and validity, of the dependent variable also have to be considered when evaluating research design.

### **Reliability of the dependent variable**

Since respondents are not being asked to participate on repeated occasions, the reliability of the dependent variable cannot be ascertained. Therefore, it must be assumed that this variable is unreliable until the study can be replicated.



### **Validity of the dependent variable**

To determine the validity of the dependent variable, it is necessary to obtain evidence which indicates that the variable measures what it is supposed to measure (Christensen, 1988). This variable has face validity and can be supported by the literature. The construct 'ability' can be clearly defined and related to the behaviour of approaching relatives to discuss donation issues. The measure of ability, by Question 30, is a simple one, which requires a clearly delineated response: yes, or no. Convergent validity is the third aspect that has to be assessed. This cannot be assumed at present, although data that indirectly measures ability to discuss donation is also generated by this questionnaire. Question 29 (see Appendix 7) asks if the respondent has ever undertaken the behaviour of donation discussion, whilst Question 32 focuses on the incidence of assessment for donation potential.

The literature suggests that it is first time that this variable appears to have been measured within a large-scale survey of nurses' behaviour relating to the donation process. Obviously replication of the study is needed before any firm conclusions can be made about the reliability and validity of this dependent variable. However, for the purpose of the present research, ability to approach relatives, and discuss donation, is the behaviour that needs to be examined, and Question 30 clearly addresses this construct.

The relationships between the independent and dependent variables are to be examined further, qualitatively, during the second phase of the research, Study Two, which has the following objectives:

- To explore the influence of previous experience of organ or tissue donation on the meaning that the donation process holds for the nurse.
- To explore the role of the nurse in the donation process.
- To explore nurses' feelings about participating in donor identification and donation discussion.

- To discover the extent of the participation that nurses believe they can realistically achieve in the donation process.
- To identify the chief concerns of nurses, when considering a more active part in the donor identification, and donation discussion stages of the donation process
- To discover details of the support nurses believe to be helpful, for them, when caring for potential donors and families.

The attitudes and knowledge of future nurses form the third phase of the research. The rationale for this is reflected in the objectives for Study Three:

- To determine if student nurses have similar feelings about organ and tissue donation as qualified nurses.
- To identify any shifts in attitudes or knowledge by comparing student and registered nurses' data.
- To explore, albeit superficially, the concept of socialisation effect on attitudes and knowledge to organ and tissue donation, during pre-registration nurse education.

In this phase of the research, the independent variables reflect those being explored in Study One, whilst the dependent variable is knowledge score. This variable is determined by the scoring of correct and incorrect answers to questions 1-17 contained within the first part of the Organ Donation and Transplantation Belief and Knowledge Questionnaire (see Appendix 10). Further details of this tool will be presented in Chapter Four.

The emphasis on psychosocial factors directs one towards theories derived from social psychology to assist the process of describing and explaining the research findings. The theoretical framework for this investigation will be discussed next.

## Theoretical framework

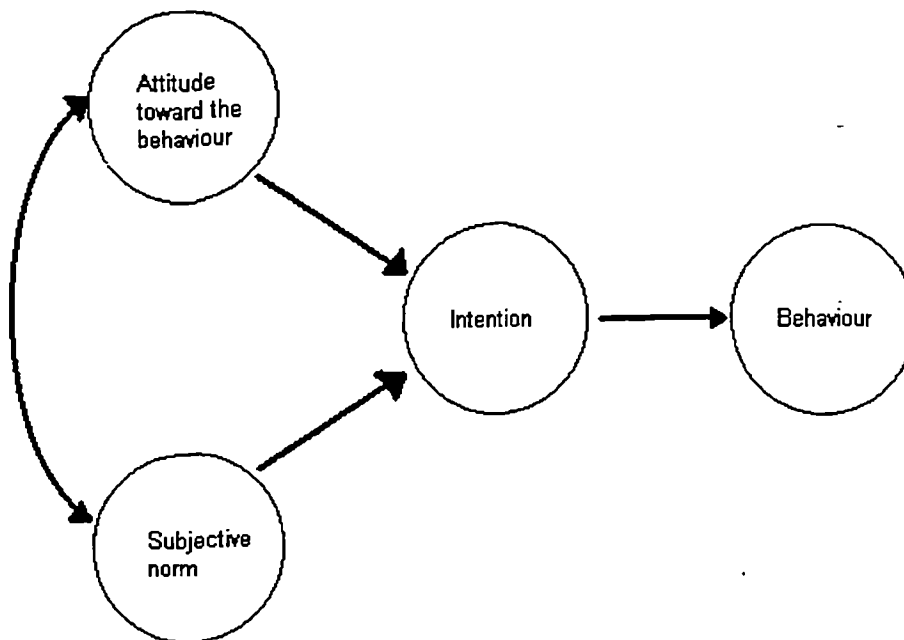
The theoretical framework most closely allied to the concepts to be investigated is Ajzen's theory of planned behaviour (1985). This was used, despite minimal supportive evidence for its use within the field of nursing, to identify factors that might be attributed to influencing nurses' participation in the donation process. These were to be explored to enhance understanding of nurses' behaviour related to the donation process, and to identify any previously undiscovered, or discounted, intervening factors. The rationale for this choice will be now be discussed.

### The theory of planned behaviour

The theory of planned behaviour is an extension of Fishbein and Ajzen's theory of reasoned action, which was developed in the middle part of the 1970s. According to Hewstone et al. (1997), the earlier theory had been widely used as a framework for social psychological investigations focusing on attitudes and behaviour. A search of the BIDS database uncovered plenty of examples of research that used either the theory of reasoned action, or that of planned behaviour as the theoretical framework. In the years 1994 -1998, 107 studies were found to have used the theory of reasoned action. In the same period, 88 reports of studies using the theory of planned behaviour were identified. Topics of these studies ranged from beliefs about substance abuse, to the prescribing of antibiotics in managed care settings. Such evidence provides support for the theory of planned behaviour as the theoretical framework for the present research, whilst also demonstrating the usefulness of the model, within health care research, where behaviour, and behavioural intention, have been investigated.

Figure 3.1 denotes the proposed interrelationships between the different variables within of the theory of reasoned action. In Figure 3.2, there is a visual representation of the theory of planned behaviour. Comparison, of the two models, helps to elucidate the subtle differences, or modifications, made by Ajzen.

**Figure 3.1: Theory of Reasoned Action (from Ajzen & Madden, 1986)**



Two determinants of behavioural intention, attitudes and subjective norms, were identified. Within each of these constructs are beliefs that are relevant to the behaviour. Fishbein and Ajzen (1980) argued that behavioural beliefs include issues such as the costs that might be incurred by the behaviour. Other beliefs, normative ones, were believed to underpin subjective norms. The normative beliefs focus upon the reactions of others and perceptions of whether these other people would approve or disapprove of the intended actions.

Fishbein and Ajzen (1980) indicated that there must be a willingness to perform the behaviour and, consequently, the behaviour must under the individual's volitional control. Nevertheless, Ajzen became uncomfortable with this

assumption, and highlighted this by suggesting that even mundane voluntary activities, such as driving a car to the shops, might be obstructed by mechanical problems with the car, actions that are not under the driver's control (Ajzen and Madden, 1986).

In light of the concern over the extent of control that it is possible to have over behaviour or behavioural intention, Ajzen, in 1985, extended the above theory of reasoned action, to include assessment of the extent of control that an individual might have over some planned behaviour. Thus, the concept of behavioural control altered the theory of reasoned action, and become known as the theory of planned behaviour, presented in Figure 3.2.

**Figure 3.2: Theory of Planned Behaviour (from Ajzen & Madden, 1986)**

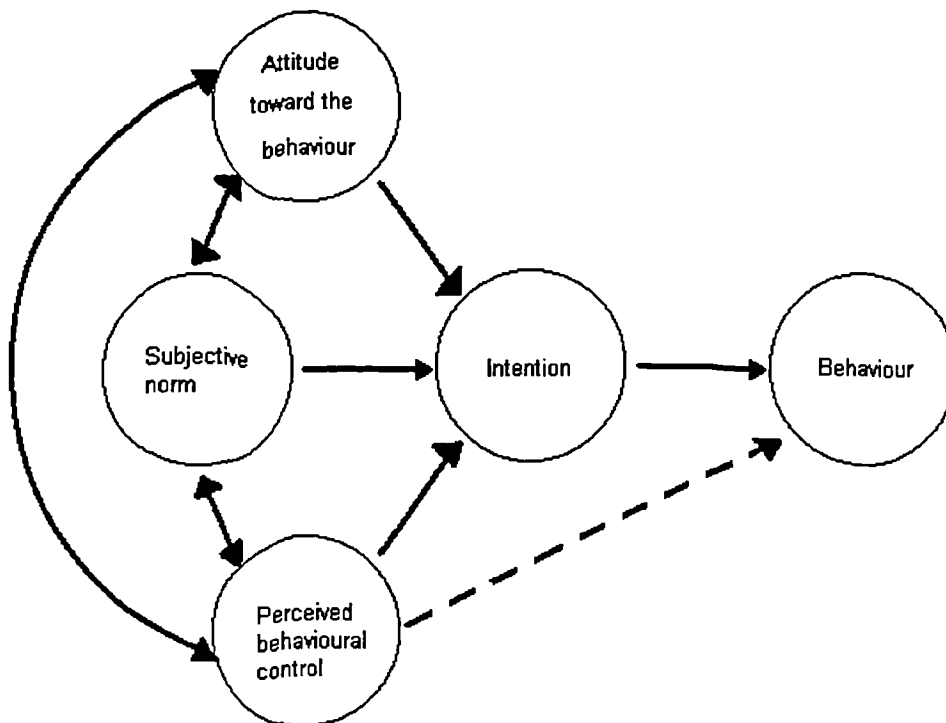


Figure 3.2 highlights the proposed interrelationships between perceived behavioural control and behaviour. Ajzen incorporated the construct 'perceived behavioural control' into the behaviour prediction equation because he proposed

that it is possible to measure an individual's belief about how easy or difficult the actions might be. As with attitudes and subjective norms, Ajzen argued there were beliefs that underpinned perceptions about ability to perform any future actions, and these included beliefs about resources and opportunities. The more of these that the person thinks they have, and the fewer obstacles that can be foreseen, then perceived behavioural control should increase accordingly. Ajzen suggested that past experiences influence perceptions about future behaviour as does information, passed on by others, gained through their experiences or encounters with the behaviour. These can have positive and negative effects upon the person's perceptions.

There may be a direct influence upon intentions by these perceptions of control without any mediation by attitudes and subjective norms. Ajzen and Madden (1986) explain this by suggesting that individuals, who feel that resources and opportunities to perform the actions or behaviour are absent, would be unlikely to form strong intentions to participate in this behaviour, even if the attitudes and subjective norms were supportive of the behaviour.

Applying this analogy to the focus of the present research, one would expect that nurses who feel that they do not have the knowledge to identify someone as a potential donor, and who work in an area where deaths rarely occur, would be unlikely to consider participation in the donation process, even though, personally, they may see organ donation in a favourable light.

A further interrelationship, identified in Figure 3.2, shows a direct link between perceived behavioural control and behaviour. Ajzen and Madden (1986) are not convinced that, in all circumstances, behaviour is mediated by intentions. Intentions may not always be a precursor to behaviour. The actual availability of resources and opportunities, actual control, may accurately be reflected by perceived behavioural control and thus exert a direct influence upon behaviour.

Taking the separate constructs of the theory, Ajzen and Madden (1986) suggest that perceived behavioural control works with, or without, the influence of attitudes and subjective norms. In two studies presented to justify the propositions contained within the theory of planned behaviour, Ajzen and Madden (1986) revealed that the addition of perceived behavioural control, increased the predictor properties of behavioural intention, by impacting upon motivation towards the behaviour.

The constructs contained within the theory of planned behaviour fit well with the concepts to be investigated within the current research. Other theories were considered, such as Festinger's theory of cognitive dissonance, but were discounted, because they did not appear to provide a sufficiently comprehensive framework for the complexity of variables to be explored within the research. By using the theory of planned behaviour as the framework, an additional purpose is being served, that of testing the robustness of the theory to help predict behaviour, that is thought to evoking a multitude of conflicting emotions among the participants.

The systematic process of decision-making about research design necessitates deliberation over the ontological, epistemological and methodological tenets that relate to the research questions (Patton, 1990). The research was to be phased to enable the exploration of different issues. Consequently, evaluation of appropriate methodologies was required. Consideration of these led to the adoption of a combined approach to accommodate the emergence of anticipated variations in the beliefs and perceptions related to the phenomena.

The rationale, for the choice of a combined approach to studying the phenomena in the present research, will be discussed now.

## Rationale for the combined approach

A combined approach was deemed to be the most appropriate for this investigation due to the desired outcome of anticipated completeness, a phenomenon that neither qualitative nor quantitative, if used alone, could accomplish. Supplemental to this, the combined approach would also assist the cross-validation of the findings (Goodwin and Goodwin, 1984 p.380).

The key focus of the investigation is on human experiences, with the three phases of the research designed to explore nurses' experiences of death, dying and donation, through the use of survey, and interview. The combination, of these methods, is anticipated to enhance the quality of the scientific process, and add depth and breadth to the research. When exploring human behaviour, the art of the discovery appears to lie in the appropriate choice of method that allows the foci of the research to be teased out in the most complete manner.

Establishing the extent of association between two or more variables requires a predominantly quantitative methodology, to facilitate statistical analyses, calculating the significance of the findings. Therefore, the description of, and relationships between, attitudinal, and societal constructs, and perceptions of behaviour can be investigated effectively using questionnaire, although there are concerns, such as validity, that must be considered (Kirk-Smith and McKenna, 1998). Human behaviour is influenced by many factors, which may be discounted or rejected if a wholly quantitative stance is adopted. Subtle or less significant relationships, that to the individual are very important, may be disregarded. To reduce this risk, a qualitative approach was selected to uncover the meaning that participating in the donation process holds for a selection of nurses.

This qualitative approach reflects the philosophy of phenomenology which is, according to Crotty (1996), a search for reality. The research design of this study



fits with the hermeneutic school of phenomenology (Cohen and Omery, 1994), the purpose of which is to re-construct reality, through interpretation of the data (Patton, 1990). To achieve the reality, one must reach into the minds of others to discover what the object, in this case organ donation, means to the person, in an attempt to understand or make sense of behaviour or reactions to that object. Hermeneutic phenomenology awakens our sensitivity to ourselves in the world of nursing and health care and, consequently, has a place in nursing research.

The combined use of qualitative and quantitative methodologies has been the subject of much debate partly because the two main theoretical perspectives reflect a dichotomy in research. Consider a continuum where, at one end, sits the positivist perspective, which uses a deductive process to test theories and establish the existence of causal relationships between variables. Within this paradigm, knowledge is attained through traditional objective forms of measurement with the aim of predicting events. At the other end of the continuum, however, is the qualitative perspective, which relies upon inductive methods to understand the meaning of phenomena in the naturalist setting (Mason, 1993). The aim of this perspective is to generate, rather than test, theory.

By tradition, when deciding to use one, or other, of the main theoretical perspectives, one becomes bound or constrained by its epistemology. The chosen paradigm provides a conceptual framework which guides, and organises, the research (Goodwin and Goodwin, 1984). Those in favour of a single approach would argue that there should be no merging or combining of the two perspectives because they are inherently different. Denzin and Lincoln (1994 p.4-6), advocates of the qualitative perspective, argue that the different commitments to the style of the research, the different epistemologies, and different presentation styles, can pose problems when using the two perspectives together. Denzin and Lincoln's views contrast with those of Krahn et al (1995) who propose that, by combining methods, researchers can maximise the strengths of each whilst also providing a mutually defined context for interpreting their results.

Limiting approaches to a single perspective can be problematic for the discipline of Nursing, which focuses on human beings, as individuals or as part of a larger society. The topics that are of interest to nurse researchers have a tendency to span the traditional disciplines (Mitchell, 1986). Therefore, combining qualitative and quantitative methods can be advantageous in the way proposed by Krahn et al (1995). Patton (1990) purports that qualitative and quantitative methods are alternative, but not mutually exclusive, strategies for research. Goodwin and Goodwin (1984) suggest that rigidly linking paradigms with method will, almost certainly, lead to research that is conducted inappropriately, thereby producing findings that lack credibility.

Mason (1993) expressed concern that, without a thorough understanding of the perspectives' theoretical bases, a lack of rigour may result if a combined approach is adopted. Each of the methods chosen must be selected for the right reasons. Each method must be complete in itself, and each must have proven rigour. Each method must be valid, complementary and supportive to the other methods. It is these principles, therefore, that guided the design of the present research.

It is important that clinically, and academically, based nurses recognise the uniqueness of an individuals' experiences and interactions, studied using a qualitative approach, whilst at the same time, identifying common factors, arising from that event or experience, from which one can make predictions. The latter requires a quantitative approach (Myers and Haase, 1989). Aroskar (1991), responding to phenomenological research by Wolf (1990), emphasised the importance of examining the feelings and experiences of health professionals. She purported that the understanding, generated by this activity, helps to meet the needs of those in receipt of care, and enables effective support mechanisms to be developed for those carrying out the care.

It is not uncommon, therefore, for researchers on both sides of the qualitative-quantitative divide to use a variety of methods to try to increase understanding of the phenomenon being investigated. To increase understanding of nurses' responses to the donation process, and discover factors that may have a greater influence on behaviour in North Wales, quantitative and qualitative explorations are appropriate.

Consequently, there are three key stages to the research:

- **Study One:** A survey of registered nurses' affective and cognitive components of attitude to organ and tissue donation. The objective was to quantitatively explore the association between affect, cognition and perceived ability to discuss donation issues, among nurses working in North Wales, and a comparison health region. These findings were to be further developed, through the use of Study Two
- **Study Two:** a qualitative inquiry, using semi-structured interviews, with nurses from the sample used for Study One, to explore, phenomenologically, the meaning that donation holds for these nurses, within their personal and professional environments. This insight was to be further enhanced by Study Three:
- **Study Three:** A comparison of the attitudes and knowledge levels, pertaining to organ donation and transplantation, of future nurses, with those of qualified nurses, to identify any similarities, or differences.

The initial investigation, through the use of survey methods, facilitates the framing of research problems in subsequent qualitative work that utilises the philosophy of interpretative phenomenology. Thus, in this way, the use of two complimentary methodologies provides an enlarged contextual and procedural framework to guide the analysis and interpretation of the findings, and

consequently increase understanding of nurses' feelings about the donation process. Hammersley (1996 p.167) identified the use of the combined approach in this way as 'facilitation'.

Swanson-Kauffman(1986 p.60) summarised the rationale for methodological choice by stating: " Simply put, we should let our nursing questions guide our methods, while being ever aware that the methods will shape our answers."

The thesis progresses by expanding on the methodological aspects of the research in the next chapter, Chapter Four.

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## Chapter Four: Research Methodology

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### Chapter overview

This chapter continues the process of contextualisation by focusing further on the methodologies of this research, thereby developing the rationale discussed in the previous chapter. Patton (1990) asserts that the chosen methodology for a research, whether it be associated with single or combined paradigms, should allow the researcher to compile an accurate picture of the phenomena being investigated. The credibility of the research findings depends greatly upon the methodological planning.

Patton (1990) recommends that researchers should consider a number of issues when deciding which method or methods would be most appropriate to meet the aims of the investigation. These include: who will find the findings useful?; the type of information that is needed; the future use of the any information; the timing or urgency of the need for information; and the resource constraints. “Any given design is necessarily an interplay of resources, possibilities, creativity, and personal judgements by the people involved.” (Patton, 1990, p.13).

The research design, sampling strategy, the data-collection methods, including reliability and validity issues relevant to the underlying paradigms, and ethical considerations, pertinent to each of the distinct studies, will be detailed here, to clarify the research process.

## Research design

Research design is, according to Parahoo (1997a), the plan that outlines how, when and where data are to be collected and analysed. The rationale for the use of a combination of methods has been discussed earlier (see Chapter Three). However, for completeness, it is necessary to describe further the details of the design of each phase of the present research. This begins with details appertaining of the target population, and continues with Study One, the quantitative exploration of registered nurses' attitudes and knowledge of donation, and the effect of these on perceived ability to participate in the donation process.

### The target population

As with any research project, quantitative or qualitative, a major aspect of design concerns the sample, the source of the data that is to be collected. Within the two methodological paradigms, sampling is approached in different ways. However, there are general aspects of sampling that can be applied to both, one being the target population.

Polit and Hungler (1989) defined the target population as the entire population in which the researcher is interested and to which the results might be generalisable. For the purpose of this research, the target population comprises of nurses with recordable qualifications on Parts 1, 2, 7 and 12 of the Professional Register of the United Kingdom Central Council for Nursing, Midwifery and Health Visiting (UKCC). Thus it contains approximately 527,000 nurses throughout the UK (UKCC, 1996). Logistically, however, not all of these nurses can be included in the investigation all of these nurses, since not all of the nurses registered with the UKCC are involved with the care of dying patients. Therefore, a strategy for sampling was devised.

To enhance the generalisability of the findings to the wider population a sample, of the population, should be representative of the larger target population (Parahoo, 1997b). To achieve this, a sampling strategy was formulated to restrict the target population to approximately 168,000 nurses and which are summarised in Table 4.1.

<b>Table 4.1: Characteristics of the target population</b>
Nursing qualification recordable with the UKCC (Parts 1,2,7&12) Graded 'D' to 'I' Clinically based in ICU, CCU, A&E, medical area or surgical area

Clinical nurses in the UK are graded according to their role in the ward team and the skills that they possess. When the study was being designed, a nationally agreed classification of grading applied in the National Health Service hospitals: beginning at grade 'A', and ending at 'I'. Grades below 'C' were allocated to health care assistants, who help with patient care but always work under the guidance of a nurse registered with the UKCC. Accordingly, nurses holding recordable qualifications on the relevant parts of the UKCC register, were graded, within the grading scale, according to job description, beginning at 'C' and ending with 'I'.

The decision was taken to exclude grade 'C' nurses from the sample because this grade of nurse was thought to have less responsibility for making decisions about patient care, and accordingly, donor potential. These nurses would, in theory, be working under the supervision of grades 'D' upwards who would make the major care decisions.

The sampling criteria required the nurse to be based in an area of acute hospitals where adult patients might die. The decision to restrict the sampling to the acute hospital settings was taken on resource grounds. The majority of asystolic deaths and all of the systolic brain-stem deaths formally diagnosed as such, occur within the acute hospital setting. It was not feasible, in terms of time and resources, to

include in the investigation nurses working in hospices and homes, where, it is acknowledged, deaths do occur. Therefore, the sampling frame restricted inclusion to hospital-based nurses, working in specialist and general areas of care such as intensive care units (ICU), coronary care units (CCU), accident and emergency departments (A&E), medical wards and surgical wards.

## Seeking access for sampling

To facilitate the identification of any influencing factors affecting the North Wales region, and contributing to the lower donation figures from this region when compared with the UK average, it was important that a comparison group, from another region within the UK, was included in the study. This geographical region was selected for its convenience for the researcher, as it was important that research costs were kept within the allocated budget. Travel time and accessibility, from a temporary base for the researcher located in the East Midlands of England where accommodation was offered, were considered before the choice of region was made. Despite the obvious limitations that the non-random choice of location imposes on this study, every effort was made to minimise bias during the sampling process.

A directory of NHS hospitals and trusts (Robertson, 1994) was consulted to identify the acute general hospitals in the regions within travelling distance of the researcher's bases in Bangor (North Wales) and Nottingham (England). A letter was sent to the Director of Nursing, at each hospital in the various NHS trusts, requesting permission to enter the premises and approach nursing staff. Nine Trusts were identified in this way: three Directors did not reply to the request letter; one replied but refused access, giving valid reasons for the decision; and five Directors gave their permission to use the hospital, and its nursing staff, in the research.



Consequently, in North Wales, permission was given to include, in the sample, nurses employed by three acute NHS Trusts, one of which contained two hospitals. In the Trent health region of England, permission was given to sample nurses working in two locations within the county of Leicestershire.

Unfortunately, these were within the same urban conurbation, which places an obvious limitation on the investigation. However, it lessened the demand on resources and, as no further research sites became available, the situation had to be accepted.

## **Approval for the research**

Applications seeking approval for the research, in relation to ethical issues, was a lengthy process and one that revealed the lack of standardisation for ethical submission among the NHS trusts. Permission was first sought from the local ethics committee serving the hospital close to the researcher's base. A formal submission for review by the committee was not requested due, apparently, to the non-involvement of patients in the research (See Appendix 3).

Once approval from the Director of Nursing, at each of the participating hospitals, had been obtained (see Appendix 4), a meeting was arranged with clinical managers to ensure that they, too, were conversant with the research details. For the three hospitals in North Wales, discussions took place during the monthly management meeting and, following the presentation and discussion, copies of the questionnaires as well as a copies of the research proposal were left with each of those present. A contact telephone number was also given, thus enabling individual questions to be answered directly.

The two hospitals in Leicestershire had different procedures to follow. After the initial application was sent to the Director of Nursing, at both hospitals, for

approval, one required further submission, of the research proposal, to the nursing research committee, who requested an attendance at their meeting.

The Director of Nursing, at the other hospital in Leicestershire, requested that a meeting with the nursing directors of the surgical and medical directorates at that hospital should be held to discuss any questions that they might have

These meetings, in each of the hospitals participating in the research, proved to be very useful for all concerned. Assurances given focused on beneficence, non-maleficence, and confidentiality. All those present expressed satisfaction with the attention that had been paid to these important issues.

Further meetings were arranged, with clinical nurse managers, to request access to information listing the names of the nurses working on each of the wards that fell within the sampling criteria identified in Table 4.1. Details of designation, grade and place of work was required to ensure that the inclusion criteria were met. In North Wales, this process proved relatively unproblematic, except in one location. Despite letters and telephone calls no staff lists were produced. Eventually, this site was excluded from the sampling process and the research, reducing the sampling sites in North Wales to three. Overall, these stages of the sampling process took approximately 10 months to complete.

Further details of the methodology will now be presented, beginning with that appertaining to Study One.

## **Sampling in Study One**

Once the sampling frame had been compiled and the staff lists obtained, the process of identifying a randomised, stratified, sample began. The minimum

sample size was calculated using a computer statistical package, 'ARCUS ProStat'. After identifying the approximate target population size (168,000), an estimate of the incidence of non-discussion within that population (approx. 80%), and the acceptable error (5%), the minimum size was calculated to be 245. However to minimise the risk of Type II error, incorrectly accepting a false null hypothesis (Polit, 1996) the sample size was increased. The decision was taken to randomly select 50% of the nurses within the sample population, which would increase the sample to 776 nurses.

The sample population was also stratified for grade, to maintain a high level of representativeness. Mitchell and Jolley (1992) suggested that stratified sampling has advantages over simple randomisation because it leaves less to chance. By matching for certain characteristics the researcher is increasing the likelihood that the sample will be representative of the target population. These authors also point out that stratification of a randomised sample reduces the size of the sample required to minimise the risk of sampling error. Stratification is time-consuming but results in a sample whose representativeness is enhanced (Haber, 1994).

The stratification process involved scrutinising the nursing lists, for each of the wards, to identify the nurses of grade 'D' upwards. The proportion, of each of the grades, was identified at each location. Slightly different proportions were obtained for each location, reflecting the variations in skill mix in each area. Each, of the subjects, was allocated a unique number for that location. For example, all of the 'D' grade nurses on the lists of the medical directorate in one hospital were allocated a number and these numbers were entered into a computer. The computer programme, ARCUS ProStat, produced, at random, a list of numbers that were printed out. The first 50% were identified and matched with the numbers on the corresponding staff lists for that directorate. These nurses subsequently formed the sample for inclusion in the research.

The same process was undertaken for each directorate in each of the five locations, thus producing a sample that reflected the grade profile for the population. Although this process was time-consuming, it was necessary because a simple randomised sampling strategy may have resulted in a sample that did not reflect the skill mix among the clinical areas, by omitting groups of nurses, and contributing to the invalidity of any subsequent findings.

## **Data-collection: Study One**

Study One uses self-administered questionnaires to measure nurses' responses to attitudinal and knowledge variables that have been implicated, in the literature, as influencing donation behaviour, and which were discussed in the previous chapter.

The advantages, and limitations, of this method are well documented and have been carefully considered. Flexibility and the broadness of scope have been cited as the greatest advantages of surveys in research (Polit and Hungler, 1987). If well designed, they can generate a substantial amount of information, about a wide variety of topics, to a relatively large number of people. However, as discussed recently by Kirk-Smith and McKenna (1998), surveys, particularly questionnaires, have their limitations. These include the relatively superficial nature of the collected information; the limited opportunities to probe or inquire further when apparent contradictions are noted; the lack of control that the researcher has over the independent variables which can reduce the confidence in any correlations or conclusions about causality that may be inferred from the data; and the often underestimated time demands incurred during the planning, distribution and processing phases of the study.

According to Denzin (1989) questionnaires tend to reflect the individual's reaction, or response, to statements, or questions, that are specifically focused at

a single point in time. The data-collection tools used in Study One, are described now.

## **The research instruments**

Two questionnaires were to be used in this investigation, the first focusing predominantly on affective attitudinal factors to donation, whilst the second measures the cognitive aspects. Details of each of these will be given now, beginning with the Organ Donation Attitude Scale, originally devised by Paris and Katz (1986).

### **The Organ Donation Attitude Scale**

This instrument had been used in earlier, small scale, study of nurses attitudes to organ donation and transplantation, undertaken at the beginning of this decade (Kent and Owens, 1995; Kent, 1991). Permission, for its use, was given by Parisi, in 1989 (see Appendix 5). Searches of the available literature suggested that the variables, being measured by this questionnaire, were still relevant, despite four years having elapsed since the completion of the earlier study and the commencement of Study One. Data, relevant to the research questions, could be deduced from the questionnaire. Therefore, the questionnaire was selected for a number of reasons:

- The content is supported by the literature
- It offers a two dimensional approach to the study of attitude - clearly identifying positive and negative feelings to organ donation.
- Reliability and validity were assessed as being satisfactory in an earlier small study with a similar target population.

- The scales, used in the questionnaire, are appropriate to attitudinal exploration and are familiar to the nurses.

It is a self-report questionnaire, that uses a predominantly Likert-type design and is divided into two sections. (A copy of the organ donation attitude scale can be found in Appendix 6). The first section measures positive and negative dimensions of attitudes to organ donation and transplantation, using 46 statements. The positive scale focuses on the humanitarian benefits of organ donation, and feelings of self worth that are reported to follow act of indicating a willingness to donate parts of the human body. The negative dimension focuses on fears of mutilation, fatalism and the fear of premature death if a donor card is signed. The literature, that identified these as interfering with donation behaviour, was reviewed in Chapter Two.

The second part of the questionnaire asks for nominal level responses to a variety of questions assessing the wishes of the respondent to have a human transplant; an animal transplant; and a blood transfusion. The respondents are also asked to indicate if he/she is willing to donate blood; willing to donate organs/tissue after death; and to state post-mortem disposal intentions (burial, cremation, freezing or donation for research).

After reflecting on the findings arising from the earlier use of the questionnaire (Kent, 1991) a small number of modifications were made, and some additional questions inserted. This was intended to increase the relevance of the questionnaire to serve the purpose of this study.

Changes have been made to the design and to the scoring of the questionnaire. The design of Parisi and Katz' (Parisi and Katz, 1986) original questionnaire required respondents to indicate, in numerical format, the strength of their response alongside the statement. Comments, made informally following the

earlier study, instigated the alterations to the format of the questionnaire. The scoring was altered, for ease of analysis, to the following scale:

Strongly agree = 6    agree = 5    slightly agree = 4

Slightly disagree = 3    disagree = 2    strongly disagree = 1

Furthermore, the response scales are now pre-printed, so that respondents circle the appropriate response, instead of writing in their score. Pilot testing of the questionnaire, on nursing colleagues, who did not form part of the main sample, indicated approval for the revised format.

The content of the questionnaire was also modified, slightly, by the addition of four questions inserted at the end of the questionnaire. The first two were intended to elicit specific information related to 'Opting-Out' and 'Required Request', two possible changes that, in the future, might be made to the current donation system in the UK. The third addition, Question 60, enquired about previous experience, personal or professional, of the donation process. Question 61 addressed knowledge of the NHS Organ Donor Register, a database that was launched in 1984 by the UK government and which had been active for at least six months when data collection took place.

Consideration has to be given to the instrument's ease of use. Likert-type of scaling, used in this questionnaire, are frequently employed by social scientists in research and are familiar to many nurses and easily understood. The Likert scale has been called a 'subject-centred scaling procedure' (van-Alphen et al., 1994) which concentrates on the individual placing herself at some point along a continuum. All the scores for that dimension are then summated facilitating identification of fine distinctions among people with different opinions or points of view (Polit and Hungler, 1987). The set of possible values for each dimension make up the final scale, maximum and minimum, for measuring the concept

(van-Alphen et al., 1994), in this case, the positive and the negative attitude strengths. The key advantage of Likert scaling, that of unidimensionality, is purported to alleviate to some degree, the random error that can occur when the items are viewed individually (van-Alphen et al., 1994).

### **Reliability of the organ donation attitude scale**

The reliability and face validity of the organ donation attitude scale, had been assessed, first, by Parisi and Katz (1986), who developed the tool. Reliability of an instrument gives an estimate of the proportion of the total variance that is not due to error (Oppenheim, 1992). Chronbach's Alpha was used to measure this. In the earlier study of nurses attitudes to donation (Kent and Owens, 1995; Kent, 1991) the following alpha ratings were obtained:

Positive scale = 0.91 (n = 112 for 23 items)

Negative scale = 0.89 (n = 112 for 23 items)

These compared favourably with the alpha scores reported by Parisi and Katz (Parisi and Katz, 1986):

Positive scale = 0.89

Negative scale = 0.82

A maximum internal consistency score that could be achieved is 1.00. Therefore the reported scores for the sub-scales indicate that the tool generates acceptable consistency of response. Parisi and Katz also tested the independence of the two sub-scales to measure relatively independent attitude dimensions. Pearson's Product Moment Correlation was used and a correlation of 0.003 was obtained



which confirmed Paris and Katz' theoretical expectations. Although Polit and Hungler (1987) state that reliability remains unproved until the tool is retested on an identical sample using the 'test-retest' method, it is virtually impossible to achieve this with any certainty when exploring human behaviour. All of the issues concerned with measurement error, particularly personal factors, can affect the results and thus, the reliability. This tool has been used, to date, with two different samples, and the reliability scores using Chronbach's Alpha are consistently above the 0.8 level for each of the independent dimensions.

### **Validity of the organ donation attitude scale**

Selection of a tool must also involve the assessment of the tool's validity, because, as Nolan and Behi (1995) advocate, validity is at the very heart of any research project. As Sajiwandani (1996) comments, there are concerns about the truth of responses particularly when data is obtained through questionnaire and interviews. Validity refers to the extent to which a questionnaire measures what it is supposed to measure. This is much more difficult to establish than reliability and it helps to classify validity into three types (Polit and Hungler, 1987):

- Content validity, which is concerned with the representativeness of the questions. It is quite a subjective issue because it rests on judgement. However it is important that the literature review highlights for the reader the important areas included in the study.
- Criterion-related validity refers to the instrument's ability to relate to another external indicator or criterion that has been shown to be reliable and valid. It is widely used in applied clinical research.
- Construct validity is concerned with the underlying issues that surround the phenomenon being studied and looks at the interrelationships between these and the related theory. Two methods of assessing construct validity have been suggested. The first looks at convergence: evidence that indicates the similar

results when the phenomenon is tested in different ways. The second is known as discriminate validity, which refers to the ability to isolate the construct being measured from other similar constructs.

In view of the difficulties that are faced when trying to support validity, Polit and Hungler suggest that researchers should adopt multiple measures in their investigations. The strengths of each measure should complement one another in the quest to find out 'the truth', thus supporting the recommendations of Weinholtz (1995) and Hammersley (1996).

Assessing the validity of this questionnaire, and any others designed to measure attitudes to cadaveric donation, is not easy, particularly when one considers the issue of criterion-related predictive validity. The power of the tool's predictive ability is almost impossible to establish if the criterion, to which it is being related, is the actual donation of organs and tissue after the death of the respondent sometime in the future. Intention to donate, or participate in the donation process can be recorded quite easily but actual behaviour, is much more difficult to assess and this tool does not contribute to this in any way.

Concurrent validity of this questionnaire was assisted by the collection of information about the signing of a donor card. This could, in theory, be classified as the outside indicator being collected at the same time as the questionnaire data (Eby, 1993). Hessing and Elffers (1986), during their study investigating the relationship between various death anxieties and willingness to become an organ donor, asked respondents to show their donor card once the questionnaire had been completed. They found that all the students who indicated that they had signed a donor card did, indeed, carry one. However, for this questionnaire, the actual validity of the tool, to measure attitudes and donation commitment, remains to be established. No proof of signing a donor card was requested in the earlier investigation (Kent and Owens, 1995; Kent, 1991). Nevertheless, there are times when one has to trust the respondent to answer truthfully.

Content validity is easier to determine. The concepts covered within the questions in the questionnaire can be supported by previous research studies originating from a number of different disciplines. Psychologists, sociologists, medical specialists and nurses have all studied the issues under investigation here. Parisi and Katz cited the work of Cleveland and Johnson (1975a; 1975b; 1970) and Claxton (1974) to support the design and content of the questionnaire. These studies have been examined carefully and they do indeed appear to be supportive of the underlying theoretical constructs of the tool.

Construct validity could not be established at the commencement of the research since it was not reported during the previous research by Kent (1995; 1991) nor by Parisi and Katz (1986). Factor analysis, a procedure to assess validity suggested by Fowler (1995) was performed on the earlier data (Kent, 1991) and identified clusters of related statements. Convergence did vary but was still acceptable.

Despite the shortcomings in validity, and the scarcity of studies to support reliability, it made sense to re-use this questionnaire. It performed well in the earlier study by Kent (1991; Kent and Owens, 1995) and its use in this investigation, will provide further evidence required to establish the reliability and validity of the tool.

An additional questionnaire was also employed in the present research to assess more fully the cognitive component of attitude, and the sample's understanding of issues directly related to the donation process. It was developed from one by Gaber et al. (1990) from the USA. Gaber was approached for permission to use and modify the tool in 1990, after a report of the research was presented in the journal *Transplantation Proceedings* (1990). The tool appeared to be well suited for the research that was being planned at that time. However, when the questionnaire in its entirety was viewed, it became apparent that major

modifications would be needed before this tool could be used in the UK (see Appendix 7). The questionnaire was modified and is being used, for the first time, in Study One. It will now be described.

### **The Organ Donation and Transplantation Attitude and Knowledge Scale**

The instrument was originally designed, by Gaber et al. (1990), to assess knowledge, awareness, understanding and personal attitudes of organ donation and transplantation among non-medical health professionals working in ICU, the emergency department and the operating theatre of 27 hospitals in the USA. The research enhanced the Memphis transplant services' understanding of the issues that concerned those health professionals. Gaber et al. (1990) found that a major weakness in the donation process was health professionals' attitudes to the discussion of donation, with potential donors' relatives, which was compounded by a poor understanding of brain death.

The revisions that were made to Gaber et al.'s (1990) original questionnaire were intended to increasing its relevance to the UK health care setting. These revisions were carried out using, as a framework, Oppenheim's (1992) recommendations for questionnaire development. Consideration was paid to the following:

- The relevance of the type of data collection instrument needed to meet the requirements of the study.
- The appropriateness of the method of approach to respondents which includes an evaluation of the questionnaire suitability in terms of length, confidentiality issues as well as the issue of anonymity.
- Evaluation of the sequencing of the questions, and decisions, made in relation to changes that might be needed.

- Examination of the types of questions that were included and the question wording, bearing in mind that the predominance of closed questions would curtail the breadth of the responses whilst making the questionnaire easier to process.

Pilot work was carried out in 1994, during which the layout, question wording, question sequencing, and question scaling were revised and refined. In total, three revisions were required before the final version was achieved. This resulted in a questionnaire that was reported to be understandable, appeared to encourage respondents to move onto the next questions and which generated useful data.

The planning stages provoked a series of discussions, centring on the scaling to be used. Some of the questions were very factual and, for these, a nominal scale of “yes/no/don’t know” or “agree/disagree/don’t know” were the most appropriate type of scaling. However for others, a Likert type scale was used. This facilitated understanding of the strength of feeling gained from the responses.

Assessment of potential donors is central to the focus of the research and, consequently, during the development of this new questionnaire, questions were included that asked respondents to indicate the frequency with which assessment are carried out on the continuum ‘always’, ‘usually’, ‘sometimes’ or ‘never’. This issue was addressed at the end of the questionnaire following preparatory questions that asked for information about personal donation intentions, including views on the donation of relatives’ organs or tissue, and open questions, focusing on previous experience of caring for the donor family.

There was some overlapping with concepts covered in the organ donation attitude scale, however, it was anticipated that these would help to cross-check the consistency and reliability of responses. Other issues related to the tool’s reliability and validity, are considered now, since these two concepts are

necessary as a check on the accuracy and the credibility of the instrument and the findings generated by the tool (Behi and Nolan, 1995).

### **Reliability and validity of the Organ Donation Attitude and Knowledge Scale**

The reliability of the instrument had not been thoroughly assessed prior to the commencement of the data collection phase of Study One. However, following data collection in both regions, an alpha score of .65 for 40 items ( $n = 279$ ) was obtained. The nature and the level of measurement error displayed by this finding, requires further investigation. Consequently, until reliability has been established validity is also questionable. As Oppenheim states (1992 p. 162), 'reliability is a necessary (but not sufficient) condition for validity: a measure that is unreliable cannot attain an adequate degree of validity - its error component is too great.'

Content validity has been considered, through the process of reviewing the literature, to ensure that the questions, contained within the questionnaire, cover aspects of donation not addressed by the organ donation attitude scale.

Concurrent validity cannot be established because the tool has not yet been validated by other research.

Construct validity, which tests the association between the tool, and its theoretical underpinning, is, according to Nolan (1995 p.532), 'the most important, difficult and challenging form of validity to establish'. The consensus of opinion, among researchers, is that enhancing knowledge appears to improve understanding of brain death which, subsequently, improves attitude towards the whole concept of donation (Horton and Horton, 1990; Malecki and Hoffman, 1987; Matten et al., 1991). This gains further support from Quint's theoretical model concerned with caring for the dying patient (1967). Therefore, the

rationale for the content of the questionnaire appears to be in line with the related theory.

Details of the data-collection phase of Study One, will be presented next.

## Data collection in Study One

Following sampling, a package comprising of a covering letter giving brief details of the purpose of the study and providing assurances of confidentiality (see Appendix 8), the Organ Donation Attitude Scale, the Organ Donation and Transplantation Knowledge Scale and a 'Freepost' addressed returning envelope, was sent to the selected nurses. After an interval of three weeks, a reminder was sent out. It was not possible to target the non-responders individually because of the assurances that had been given about anonymity. However, in addition to the reminder letter, a poster, thanking the nurses for their participation and reminding those who had not returned the questionnaire to do so as soon as possible was sent to each of the wards that had a member of the sample working on it. No subsequent reminders were sent, primarily, because neither of the approaches appeared to have a significant effect upon response rates - only three questionnaires were returned following the first reminder letter. An additional reason, for the lack of reminders, was to minimise antagonism of the sample

The completed questionnaires were returned using the supplied envelopes and the contents were recorded on a master sheet. This coded information was then transferred onto a computer for statistical analysis using SPSS for Windows. The respondents were identified only by a number and, if provided, the employing hospital. Data collection took place over an eight month period, longer than anticipated. Delays resulted from the permission seeking process, which took several months longer than expected. Data collection commenced in the spring of 1995. A cut-off date, for returns, was set to allow analysis to begin: 4

questionnaires were returned incomplete, and 10 were returned after the cut-off date. These were excluded from the final analysis, an outline of which will be presented now.

## Data analysis strategy for Study One

The analysis strategy for Study One was guided by the quantitative paradigm, using a commercial computer statistical analysis package, SPSS for Windows (6.1). The strategy mirrors that proposed by Polit (1996, p.14), which follows the following stages:

- Preanalysis – coding; data entry; data inspection.
- Preliminary assessments – of assumptions for inferential tests; missing data problems; data quality; and bias.
- Preliminary actions – undertake transformations/recoding; construct scales.
- Principal analyses – perform descriptive statistic; bivariate analyses; multivariate analyses.
- Interpretive stage – integrate and synthesise analyses; perform additional interpretive analyses.

Accordingly, preliminary descriptive univariate analysis of the data is to be followed by bivariate, and multivariate, analyses to identify the existence of relationships between the independent (nominal/ordinal level of measurement) variables and the dependent (nominal) variable outlined in Chapter Three.

The bivariate relationship between ordinal level variables and the dependent variable is tested using Spearman's Rank Order Correlation ( $r_s$ ). Although the attitudinal data, generated by the Likert scaling, is ordinal in its level of measurement, the selection of the parametric Pearson's Product Moment



correlation, or the non-parametric Spearman's, was debated. Oppenheim (1992) argues that ordinal measures such as those of a Likert scale can be viewed as having a linear dimension that has interval level properties. Oppenheim also emphasises that this is not strictly correct and poses a risk of reaching misleading conclusions. However, it is a stance taken by many researchers who use parametric statistics to analyse data generated by Likert scales. After considering Knapp's arguments (1990), the decision was taken to treat the data as ordinal, and accordingly, opt for non-parametric statistical tests. Regional differences observed are measured using Chi-Square Test of Independence ( $\chi^2$ ).

Multivariate analysis for association between the independent and dependent variables is to be undertaken using logistic regression. Logistic regression analyses the relationship between multiple independent variables and a single dependent variable, and is used when the dependent variable is categorical. Unlike multiple linear regression, logistic regression is a procedure that does not assume multivariate normality when predicting a categorical outcome. Whereas in multiple linear regression, the criteria for predicting outcome are based on an estimation of least-squares, in logistic regression outcome predictions are based on a maximum likelihood method (Polit, 1996). According to Polit (1996) this process estimates the parameters that are most likely to have generated the observed findings.

Logistic regression develops models that reflect an estimate of the probability that an event occurs. Thus, in Study One, the model will predict which of the independent variables, found to have a significant bivariate relationship with ability to discuss donation, have significant multivariate association and increase the likelihood that a positive perception of ability will occur. Probability is transformed into odds, or, as Polit (1996) states, the ratio of two probabilities: that of feeling able to discuss donation, and the probability of feeling unable to undertake discussion behaviour.

The independent variables that are entered into the prediction equation can be continuous or dichotomous variables in logistic regression. Therefore, all the variables identified as being significant after bivariate analysis are to be entered simultaneously as a block, as opposed to carrying out stepwise, or hierarchical methods of entry. All cases are to be included for this process, prior to a regional split being performed, which will enable overall, and regional, models to be developed. The Wald statistic is used within the model to assess the significance of the individual variables entered as predictors. As with all the statistical tests that will be performed in Study One, the level for significance is set at 0.05.

Data analysis involves the entire data set, as well as the regional ones, thus facilitating comparisons to be made. Commonalities, as well as differences, in characteristics of those who would discuss donation and those who state they would not are noted.

The qualitative data, generated by open-ended questions, is analysed using crude descriptive methods, to explore frequency of responses. The emergent issues, from Study One, form the basis for the interview schedule used in Study Two. The methodological issue of Study Two will be described next.

## **Research design of Study Two: 'talking about donation'**

The purpose of Study One is to provide an overview of feelings, beliefs and knowledge levels of nurses in the two health regions at the time of data collection. Key issues, thought to be interfering with participation in the donor identification and request stages of the donation process, are to be highlighted for further investigation. The purpose of Study Two is, therefore, to continue this exploration to discover the reasons for reactions to donation discussion and the

donation process, and to enhance understanding of the problems that participation in the donation process create. The perspectives to be explored included those who are already involved in donation discussion, those who do not want to become actively involved in the identification and request stages of the donation process, and those who might consider involvement, or who are undecided.

In order to understand the meaning of any participation in the donation process, from the nurses' perspective, a phenomenological approach was taken. Phenomenology focuses on experiences and the acceptance of experience as it exists in the mind of the individual (Morse and Field, 1996). The process of interpretation of these experiences will develop our theoretical understanding in a way that descriptions alone cannot (Cohen and Omery, 1994).

To understand the meaning that a phenomenon holds in the minds of a person, one must draw on sources of insight that will help to contextualise the information being received. Therefore, to understand what underpins nurses' behaviour, particularly in relation to the donation process, it is important that the earliest influences, for the individual, are uncovered. The path forward can then be followed. Thus, the nurses' interpretation of the participation in the donation process is related to the frame of reference that surrounds it. However, this process of interpretation depends, in part, on the prior experience or understanding on the part of the researcher. Without it, establishing a common bond between the researcher and the researched, and understanding the experiences of the researched, is difficult if not impossible (Ray, 1994). However, as with any scientific cyclical process, the end point is rarely reached. Investigations can keep proceeding because understanding, interpretations, and researchers change over time. Consequently, understanding of the phenomenon changes. Therefore, the present research has to be contextualised, so that readers, or future researchers, can understand why the investigation progressed in the way that it did, in light of the events at that time. Later interpretations of the data might vary, from that undertaken here, but it makes the findings no less valid.

Prejudgement and universality have been identified as the central positions of hermeneutics. Insight or presuppositions are not being set aside since this would hinder, rather than help, the process of interpretation, to further understand the meaning of organ donation and the donation process as experienced by the individual nurse. It is pertinent, however, to clarify these presuppositions that are brought to the investigation.

### **Description of the researcher's presuppositions**

I embarked on this investigation with characteristics that, in all likelihood, will affect the research design, data collection and the interpretative phases of Study Two. An extensive knowledge base, and direct involvement with regard to organ and tissue donation and transplantation, combined with over a decade of clinical expertise of general and specialist intensive care nursing have to be taken in to consideration when one evaluates the perspectives of this study.

Just as the various methods utilised in quantitative studies can influence the outcome of the research, the same can apply to qualitative methods, such as phenomenology, and the use of interviewing as the data-collection tool. Subjectivity must be recognised as an influencing factor but should not necessarily be seen as one that limits or detracts from the quality of the research. The skills and the qualities possessed by the researcher are crucial and have a direct bearing on the quality and quantity of the data (Morse and Field, 1996). The quality of the information, generated by the method of data collection chosen for this inquiry, interviewing, depends greatly on the ability of the researcher to establish rapport, trust and generally be seen as a person with whom it is easy and safe to talk. During the interpretation of the information, in the analysis stage of the research, the quality of the researcher affects the outcome. The researcher's insight, knowledge and powers of perceptions and sensitivity all

interfere with the end result. Furthermore, not only is the researcher seen as a factor that influences the quality of the research, so too, are the interviewees.

The researcher can only report on what he or she has been told. As Morse and Field (1996) identified, accounts and perceptions of events can differ from person to person. The purpose of qualitative research is not to determine objectively what actually happened, but rather to objectively report the perceptions of each of the participants in the setting. As a method of data collection, interviewing is the method of choice for many phenomenological researchers (Ray, 1994), because of the opportunity for face-to-face interaction between the interviewer and the interviewee. Lemon and Taylor (1997) emphasise this advantage when reporting on research that focused on the phenomenology of nursing care in a casualty department. Interviewing is widely used, yet it should not be perceived as being an easy option. Mason (1996a) emphasised that collecting data that is of good quality, through the use of interview, requires meticulous planning and attention to detail and this can take a great deal of time and effort. She supports Patton (1990), who observed that the quality of the information obtained during an interview is largely dependent on the interviewer.

## **Study Two: sampling strategy**

Issues relevant to sampling within the qualitative domain are identified by Mason (1996b). She suggests that it is important for qualitative researchers to address the key question about sampling: the relationship that the researcher wants to establish, or makes an assumption that a relationship already exists, between the sample and a wider population. The answer to this question, Mason argues, will determine the sampling strategy for the study.

The participants for Study Two reflected the criteria laid down in the sampling strategy for Study One (see Table 4.1). The sample was to be generated by respondents returning completed questionnaires in Study One. It was anticipated that the participant group of nurses would be sorted by grade and by clinical area. Such stratification would increase the likelihood that a cross-section of views of nurses would be sought.

The nurses who indicated a willingness to participate in Study Two were to be isolated from non-participants. The questionnaire responses generated by the two sub-groups were to be compared, to detect any variations in the following variables that might affect the representativeness of the sample: demographics, positive and negative attitude strengths, and perceived ability to discuss donation.

Coyne (1997) suggested that sample selection, in qualitative research, influences the quality of the research and, therefore, the process of sampling must be clearly described. The approach for Study Two is purposeful sampling, using categories of grade, clinical area, and attitude strength, as initial determinants for inclusion in the investigation. Patton (1990) discussed the rationale for this approach and suggested that the use of 'information-rich cases' facilitates in-depth study of phenomena, and identification of the important issues in the research (Coyne, 1997).

Generalisation of the findings was not an aim of Study Two. Instead, the emphasis was to be on talking to nurses of different grades and clinical areas, to begin to clarify and comprehend the range of nurses' experiences, their concerns and strategies that they have used, or might use, to cope with the discussion of post-mortem donation intentions. It was anticipated that nurses, who held strong negative attitudes to donation, as well as the nurses who held viewed donation more favourably, would be sought out to give due consideration to potentially opposing views (Pidgeon and Henwood, 1997).

## **Influences on sample size**

From the outset, it was acknowledged that sample size would be affected by the number of volunteers arising from Study One. There were also resource implications to be considered, which placed restrictions on the final sample size. Obtaining access for data collection in Study One delayed the commencement and the analysis of the survey data, encroaching into time allocated for the planning of Study Two. There was a pre-set completion date for this research and, therefore, it became important that the interviews were carried out within a five month period.

Morse and Field (1996) argue that verification of the data, as well as verification of the emerging theory, are important steps in the quest for establishing rigour and enhancing the credibility of the findings. They also advocate the importance of searching the literature to identify similar findings, in order to establish, not only the uniqueness of the work, as it is reflecting unique experiences, but also to demonstrate how the work fits in with what is already known in the field.

Rigour is required to minimise error. A criticism of qualitative studies is that they often lack control, particularly in the areas of reliability and validity. Therefore, steps have been taken to address the trustworthiness of this contribution to knowledge.

## **Trustworthiness in qualitative research**

Koch (1995) discussed three ways of establishing trustworthiness in qualitative research, which were first espoused by Guba and Lincoln in 1989: credibility;

transferability; and dependability. Credibility equates to the issue of truth-values and internal validity in the scientific paradigm. Koch (1995) suggests that this is enhanced when the researcher provides the reader with information about the actual experiences of being a researcher. To do this, however, the researcher has to develop self-awareness skills, as well as being able to, effectively, reflect on actions or experiences faced during the research. Credibility, in this way, serves to make explicit the subjective influences of the researcher on the data collection and analysis stages of the research. Trustworthiness is also enhanced by referring the analyses back to the participants for their comments to act as a double check for bias or error.

Transferability corresponds to the criteria of external validity in quantitative research. The reader must be provided with sufficient information to facilitate understanding of how the research fits in with what is already known about the subject area. The researcher should also discuss the value of the findings for those who participated in the research, or for those who might want to consider utilising the findings of the research sometime in the future.

The third criterion is that of dependability, which equates to reliability in quantitative research. It is not possible for a qualitative study to be truly replicated, but the researcher should present the reader with sufficient information to understand the processes that were gone through, to achieve the end result. Sandelowski (1986) stresses the importance of such activity by commenting that the qualitative research findings are unique. They correspond to reality, at a certain moment in time that cannot be replicated. Nevertheless, the reader or another researcher, can attempt to match the researcher's perspectives and the situation, whilst attempting to arrive at similar conclusions.



Data containing details of the nurses' experiences needed to be collected in the most accurate way. A semi-structured approach was considered to be the most appropriate for the reasons that will be discussed now.

## **Semi-structured interviews**

Semi-structured interviewing gives the researcher the opportunity to probe and clarify comments made by the participant. The discussion of issues within the interview is not so much controlled, but gently guided by the researcher (Rose, 1994). This does not mean that researchers begin this exploration without any prior knowledge or thought. Rather, existing information helps to identify the issues to be included in the interview, giving the researcher the insight and understanding that is required to know when to probe for more details or to ask for clarification.

Although an interview schedule is devised, it acts as a framework or guide and the extent of its use determines the level of structure that is generated by this approach. Rose (1994) likens the semi-structured interview to an adventure. In the course of the interaction, the researcher is taking a step into the unknown, unable to predetermine the issues that might arise, or the participant's route through them. Flexibility and open-mindedness are two essential attributes for a qualitative interviewer (Mason, 1996a).

## **Planning and using the semi-structured interview method**

Planning the semi-structured interview is essential, if the researcher is to go into the interview fully prepared, facilitating flexibility and contributing to a high quality outcome. The researcher must be sure, in advance of the interview, to

acquire the necessary social and interpretative skills to manage any challenges that might arise during data collection phase of the investigation.

Planning influences the choice of issues to be discussed, and how to raise them. The substance of the schedule developed for use in Study Two, involved several revisions to content, phraseology, the amount of detail or type of probing that might be required, as well as the sequencing of the issues and the relevant questions. The final version was piloted using three nurses who were not involved in the research project. The feelings of the participants, expressed during an evaluation discussion, were closely scrutinised.

The pilot participants did not voice any complaints about the areas of questioning and indicated that they understood what was being asked of them. They did comment, however, that they found it quite difficult being interviewed by someone that they knew. Nevertheless, they commented that they felt quite comfortable talking with me about their feelings generated by the organ donation process.

### **Content of the final version of the interview schedule**

After a period of four months, during which the schedule was reviewed and revised, the final version emerged (See Appendix 9). The main body of the schedule focused on four key areas of interest: previous experiences of the donation process; knowledge about the donation process; the donation process itself, focusing on the meaning that this has for the nurse; and views on increasing donor awareness. The sequencing, and the depth of such discussion, within the course of the interview would be controlled by the participant. Where conversation proved to be stilted, or not so free flowing, prepared questions would be used by the interviewer, to help the participant to describe their experiences or feelings more fully.

The discussion of, relatively, impersonal issues were to be encouraged early on in the interview, to help set the participant at ease. The questions were then to become focused on the more sensitive issues of the donation process by asking the participant to describe the extent of any involvement in the care of a potential donor.

The issues being explored become more sensitive and personal during the section headed 'The Donation Process'. The topics include detailed discussion of barriers to donation, and ability to talk about donation with the patient's relatives. It was important to ascertain if there were any conditions that made the nurse feel more or less able to participate in such a discussion, or any situations that were perceived as being more difficult than others.

Not all the nurses were anticipated to have experienced the donation process, therefore, the views of nurses who had little experience of caring for potential donors, or dealing with enquiries about donation were sought. Respondents were to be presented with a scenario, relevant to the nurse's area of work, and asked what he or she would do given those circumstances.

It was important that the emotions that may have been evoked, as a result of the discussion of such sensitive issues, should be resettled. Therefore, the topics that were schedule to be discussed towards the end of the interview were much 'lighter'. These included exploring nurses' needs, in relation to more active participation in identifying donation intentions, or donation request.

At the end of the interview, time was to be set aside for the discussion of any additional questions that the participant might have before being thanked for sharing their views and experiences and for giving of their time.

Once the design and contents of the interview schedule were considered to be appropriate for the forthcoming investigation, attention turned to data-collection, details of which are presented now.

## **Data collection in Study Two**

The interviews were carried out at a time and location chosen by the interviewee. It is important that participants do not feel rushed, therefore, whenever possible, no more than two interviews were arranged to take place in one day. The single conversations were to be audio-taped, once permission for the recording had been obtained. Further details of the actual process of data collection will be discussed in Chapter Six.

## **Analysis of the interviews**

In order to increase understanding of the information obtained and the meanings behind the words, the data was transformed as a precursor to interpretation. Transcription of the audio-taped recorded interviews was to be the first step in this analytical process. This would provide a ready overview of the experiences and views of each of the participants. Preliminary analysis of the key concepts arising from each interview would identify issues that would then be discussed during subsequent interviews with other nurses.

To make sense of the anticipated large volume of data, which would be generated, a process of conceptual mapping was to be employed. Northcott (1996) describes the use of such a process as an effective mechanism for data analysis and illustrated this with examples from his own research. The process involves formulating a visual portrayal of the ideas, beliefs, thoughts and

experiences of the nurses by accumulating all the ideas on to one sheet of paper and identifying the interconnections.

Further details of the actual data-collection process, that took place in Study Two, will be presented in Chapter Six, as this will facilitate greater understanding of the data, in accordance with the qualitative domain.

Turning now to the design of Study Three, the phase of the research that focused on the nurses of the future, whose responses are to be compared with those of qualified nurses generated in Study One.

### **Design of Study Three**

So far, attention has been on the sample of registered nurses in the two health regions. Such nurses are, in their everyday duties, involved with caring for patients and their relatives. As part of this care provision, the nurses would have the opportunity to ask about specific wishes or intentions that those being cared for may have when considering what they want to happen following their death.

It is important also to determine the attitudes and views of the future nurses, so that implications to practice can be identified and interventions incorporated into nurse training. This would go some way towards ensuring that the future nurses have the skills and the knowledge to deal effectively with the identification of clients' donation wishes and discuss openly issues concerned with death and dying

Afaf Meleis (1975), an eminent nursing academic, argued that it is important to achieve an understanding of the role of the nurse, because without this, it becomes more difficult to influence any socialisation of nursing students through

education. The goal of socialisation, according to Meleis, is to produce a professional who has a thorough knowledge base, clinical competency and proficiency plus a belief in patient centred, holistic care. Thus, it is evident that part of that process of understanding must include the exploration of the attitudes and views held by the student during the education period to determine where, or when, the key influential factors emerge. Few studies have focused upon student nurses and the ways that they acquire the professional qualities demonstrated by qualified nurses in these studies.

Hurtig and Stewin (1990) stressed the emotional difficulties that confront nurses when they are involved with caring for the dying, and highlight the importance of including opportunities in nurse education that enables students to recognise and confront their personal feelings and reactions to death. Such opportunities are thought to assist the student nurses to develop self-awareness and caring characteristics. Without these opportunities, the fear appears to be that nurses will develop hard, uncaring professional attributes.

Study Three explores student nurses' attitudes to organ and tissue donation, and assesses knowledge of donation and transplantation issues, prior to comparing the results with those of qualified nurses.

### **Study Three: sampling**

A convenience sample of student nurses, drawn from the cohorts of pre-registration student nurses studying at one School of Nursing in North Wales, was identified. Students ranging from those in the first 2 months of pre-registration training, those at the mid-way stage, and at the end of their course were included in the sample. In total, 224 students formed the sample population.

Numbers within each student cohort varied (see Table 4.2). The size of the beginner cohorts was greater than those at the middle and end. This phenomenon arose simply because the cohorts at the beginning of the Diploma in Nursing education comprise of students studying for entry on the different parts of the UKCC Register (Adult; Child; Mental Health; and Learning Disability). Thus the first eighteen months are called the Common Foundation Programme. After eighteen months the cohort divides and becomes 'branch' specific. The middle and end cohorts who participated in the study were all 'adult branch' students; those who were training for entry onto the adult nursing part of the UKCC register.

<b>Cohort</b>	<b>Stage of training</b>	<b>Number in Cohort</b>
Group 1	Beginning	43
Group 2	Beginning	48
Group 3	Middle	30
Group 4	Middle	34
Group 5	Middle	18
Group 6	Middle	33
Group 7:	End	18

No attempts were made to manipulate the cohorts. Consequently, there were more cohorts of students in the middle stage of their education included in the investigation. This resulted from the timing of data-collection. Inclusion in the study depended totally on attendance at the education centre on the day of data collection.

Due to time constraints one group was included twice, at the middle and at the end of the training (portrayed in Table 4.2 as Groups 5 and 7) to facilitate measurement of variables at all stages of the training.

The selection process used in this phase of the research is an obvious limitation of the study. However, in view of the lack of pre-existing empirical evidence, the use of students at a single location, chosen by convenience, can be excused because of the anticipated contribution to overall knowledge of the findings of this exploratory investigation.

The data-collection tool was developed from that used in Study One. Student nurses do not have the same autonomy, or decision-making responsibilities, as the qualified nurses. Consequently, it was neither necessary, nor appropriate, for the student nurses to be asked questions about previous participation in the donation request stage of the donation process. Similarly, questions that elicit specific information from qualified staff, who are actively involved in decision-making in the clinical areas, were removed. Therefore, a new questionnaire was devised, to best serve the purpose, and the participants, of this phase of the investigation. Details of this are discussed now.

### **The students' questionnaire**

The questionnaire was devised to measure positive and negative dimensions of attitude and knowledge to donation and transplantation. It is comprised of the following:

- eleven positive dimension statements
- thirteen negative dimension statements.
- twenty five knowledge statements
- twelve statements relating to views on the efficacy of transplantation
- one question that asked about body parts that the respondent would not donate
- one question that addressed willingness to accept a transplanted human organ
- one question asking respondents to indicate personal willingness to sign a donor card



- one question assessing knowledge of the NHS Donor register
- two questions that asked for the respondents views about alternative systems of donation: Opting-Out and Required Request.

(See Appendix 10).

## **Reliability and validity of the students' questionnaire**

In view of the substantial alterations required, to reduce two questionnaires down to one, and to ensure that the questions were appropriate for the purpose of this study, it was essential to evaluate the new tool's reliability. Polit (1996) defines reliability as “ the degree of dependability or accuracy with which an instrument measures the attribute it is designed to measure”. Chronbach's Alpha scores were calculated for the positive and negative dimensions of the new tool and the following results were obtained:

- .8405 for the positive attitude dimension
- .8444 for the negative attitude dimension.

Although these scores are satisfactory, reliability cannot be satisfied by one investigation of this size, and therefore requires further testing. The issues of validity that were discussed earlier, in relation to Study One tools, also apply for this new tool, and to prevent repetition, will not be discussed further. However, in light of the uncorroborated nature of the reliability of the tool, the validity remains unsubstantiated.

It is pertinent, now, to describe the data collection process for Study Three.

## **Data collection**

Data collection was planned for the period Spring 1995 to Autumn 1996. A meeting with each cohort would be arranged and the cohort members asked for their permission to proceed with a brief presentation of information about the research project. Opportunity was to be allotted before and after this presentation, to allow those who do not want to participate in the research to opt-out. A letter explaining, briefly, the purpose of the research will be attached to each questionnaire. This includes assurances of confidentiality and anonymity. The questionnaire and covering letter are to be distributed to the cohort members, together with a labelled envelope into which the completed questionnaire is to be placed. Instructions informing the group about the process for completing the questionnaire and returning the form to the researcher will be given. The students will not be required to write their name on the front of the questionnaire, just the cohort identifier. Participation will be voluntary and the students are to be informed that they will not be penalised in any way for non-participation. Opportunities for questions and further contact details are to be provided, to all of the students, to enable confidential discussion of any issues arising from the study.

## **Data analysis**

Data analysis will be undertaken using SPSS for Windows (6.1). Comparisons between the groups at the different stages of training, to determine any differences in attitude and knowledge scores, will be made. Non-parametric Chi-Square tests will be used to analyse the attitudinal data. However, if the criteria permits, between subject two-tailed t-tests will be used to determine differences in knowledge scores. The student nurses' responses will be converted into percentages to facilitate comparison with the percentage scores generated by the registered nurses in Study One. As in Study One, the level of significance will be set at 0.05.

## Chapter summary

In this chapter, the methodology pertinent to the research has been outlined and discussed. The design of each of the distinct, but related, studies has been made explicit, providing details of the sampling, planning, data-collection and analysis phases.

Study One aims to provide an overview of nurses' attitudes and their self-perceptions of ability to participate in the donation process, particularly the phase involving the discussion of donation intentions with relatives. Factors emerging as key influences on nurses' feelings in relation to active participation in the donation process, become the foundation for Study Two.

This further qualitative exploration, Study Two, aims to elicit the meaning of nurse participation in the donation process by exploring the effect of prior experience, and other factors identified by the interviewees.

The exploration is further enhanced by Study Three. This aims to examine the attitudes and knowledge of the future nurses, to discover any significant differences that might have implications for the duration of any interventions, directed at the present day nurses, if they indicate that they do, indeed, want to play a more active part in the donation process.

It is now appropriate to progress. The results of the investigations, for each of the studies, will be presented in the next chapters, beginning with those of Study One.

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## **Chapter Five: The Results of Study One - Qualified Nurses' Attitudes, Beliefs and Knowledge levels towards Organ and Tissue Donation and Transplantation.**

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### **Chapter overview**

**T**his chapter describes, in detail, the findings of Study One, the exploration of the nature and strength of links between variables, identified by previous research as having some degree of influence on the self-perceived ability of the nurse to discuss organ and tissue donation.

The results of the descriptive and inferential analyses, performed on the demographic, attitudinal, and knowledge data are presented to explore the relationship between these independent variables, and the dependent variable, perceived ability to discuss donation. These results are examined for evidence of regional variations which, where noted to be significant, will be highlighted and, again, discussed. The implications of the findings on the theoretical framework will be discussed in a later chapter, Chapter Nine.

## Purpose of Study One

The aim of Study One was to determine the strength of any relationship between previously identified psychological and societal variables and nurses' perceptions of ability to actively participate in the identification of potential donors, and donation request, in two health regions in the UK, using descriptive and inferential statistics. The issues pertinent to this phase of the research were presented in Chapter Three. However, it is helpful to reiterate these, in order to clarify the structure of this chapter:

- Describe the demographic, attitudinal and knowledge attributes of the sample, identifying any regional variations that emerge as a result of sampling/response bias.
- Determine the incidence of assessment for donation potential within acute clinical areas of the data collection sites.
- Collate the views of nurses in relation to the relevance of donor assessment protocols for guiding clinical practice.
- Establish nurses' perceptions relating to the most appropriate person to discuss donation issues with relatives.
- Determine if nurses' are willing, and feel able, to discuss donation issues with relatives.
- Explore the relationship between personal positive attitudes and self-perception of ability to discussion donation
- Explore the relationship between personal negative attitudes and self-perception of ability to discussion donation
- Explore the relationship between knowledge of the donation process and self-perception of ability to discussion donation
- Explore the relationship between professional factors, such as area of work, clinical grade, and professional qualifications, and self-perception of ability to discussion donation

The findings relating to the above issues are presented now, commencing with an overview of the final sample details.

## Study One: final sample details

776 questionnaires were posted to the sample population: 373 to nurses in North Wales, and 403 to those in Leicestershire. The final response rate was 42% (n = 326): 44% (n = 163) from North Wales and 40.4% (n = 163) from Leicestershire. 10 questionnaires were returned too late to be included in the analysis (8 from Leicester, and 2 from North Wales). See Table 5.1 for details of the response rates by hospital, showing the number of questionnaires sent to each hospital, together with the number, and percentage, returned.

Hospital (Region)	No. Sent	No. Completed Returns	%
Hospital 1 (N.W)	159	72	45%
Hospital 2 (N.W)	41	22	54%
Hospital 3 (N.W)	173	69	40%
Hospital 4 (L)	155	65	42%
Hospital 5 (L)	248	98	39.5%
Total	776	326	

NB: N.W = North Wales; L = Leicestershire

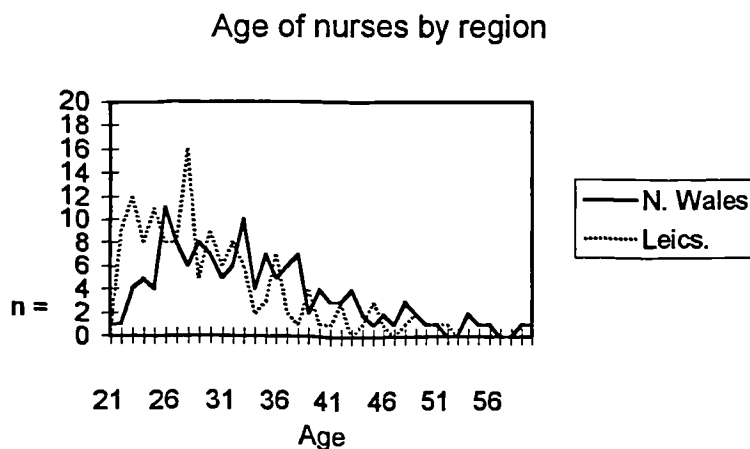
## Profile of Study One respondents

Respondents were asked to give details of demographic variables, including age, gender, professional qualifications, place of work. The results of the descriptive analyses performed will be presented now beginning with the variable 'age'.

## Age

The age of the respondents ranged, from 21 years to 60 years. The mean age was 32 years and the mode was 28 years ( $n = 22$ ). The majority, (74%,  $n = 241$ ), of the nurse respondents were under 36 years of age. There were only minor regional variations within this variable. Figure 5.1 illustrates the distribution of ages, by region, in the sample.

**Figure 5.1: Age profile showing regional variations**



In North Wales, the mean age was 34 years and the mode was 26 years, compared to a mean age of 30 years and a mode of 28 years in Leicestershire. The graph indicates clusters of ages: appearing at 26 and 33 years in North Wales, and at 23, 25, and 28 years in Leicestershire. In Leicestershire, 75% of respondents are under the age of 34 years, whilst in North Wales, this proportion occurs later, at 39 years.

The findings were compared with those produced by the UKCC in the annual statistical analysis of the live professional register (UKCC, 1996). The UKCC data indicates a national mode occurring at 30 - 34 years, whereas in this sample it was 29 years. Nationally, 53% of nurses on the live register are under the age

of 40 years. However, the proportion is greater, with 75% of respondents being under 36 years.

### **Gender**

Almost 90 % were female (n = 290) with only slight regional variations noted. The percentage of male nurses was slightly greater in Leicestershire, than in North Wales (NW: 1: 9.3%, n = 19; Leics.: 11.7%, n = 15). These figures compare favourably with the target population as, nationally, the proportion of male to female nurses is 9% male to 90% female (UKCC, 1996).

### **Qualifications**

85% (n = 277) of the respondents indicated holding the RGN qualification, and 15% (n = 49) indicated that they held the EN qualification. These figures are similar to those produced by the UKCC (1996) which indicates that 81% of the live register fall into the RGN category and 19% enter as ENs when just the two categories are compared. These calculations exclude all of the other non-general nursing entries such as mental health, mental handicap and midwifery.

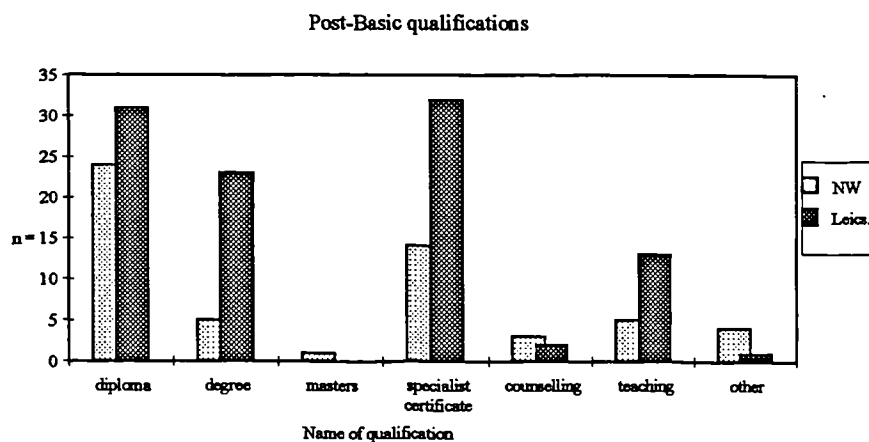
Regional variations were noted: twice as many Part 2 registered nurses (previously known as Enrolled General Nurse) took part in the study in North Wales (n= 32, 19.6%) than in Leicestershire (n = 15, 9.2%). The basic qualification of the nurses was not known when sampling took place, because the nurses were differentiated solely by grade. Grade was considered a better indicator of responsibility than basic qualification held. No attempts were made to control for register entry level variations.



## Post-Basic Qualifications

47% (n = 154) nurses indicated that they possessed additional post-basic qualification. From this, it can be inferred that the remaining 53% (n = 172) nurses have not achieved any additional qualifications since being accepted on to the UKCC register, which is in accordance with the UKCC figures. Figure 5.2 identifies the breakdown of the types of post-registration qualifications held by the sample and highlights regional variations.

**Figure 5.2: Post-registration qualifications (showing regional variations)**



The graph indicates that, in general, more nurses, in Leicestershire, appear to have studied for post-registration qualifications than in North Wales. The exceptions are in 'counselling', and 'other' courses, which include management and distance learning courses. Two possible reasons for these findings are geographical location and availability of relevant courses. At the time of data-collection, there were no specialist courses such as intensive care, accident and emergency and coronary care nursing available within North Wales. In comparison, nurses working in the specialist areas of hospitals in Leicestershire appear to have a far greater choice available to them - most of the above courses are taught at the local School of Nursing as well as at other Schools within a fifty or sixty mile radius.

There are two points to make with regard to this finding. Firstly, the specialist courses, especially those focusing on critical care, may address issues related to the donation process, or when one considers the counselling courses, enable nurses to be better equipped to deal effectively with sensitive and potentially distressing matters. Secondly, the literature implies that higher, or additional, education, beyond the basic entry qualifications, is associated with greater awareness of donation issues and a greater willingness to participate in the donation process. These propositions will be explored further by inferential analysis, the results of which will be presented later in this chapter.

Very few nurses, however, appeared to have studied at degree level or higher: 3.6 % of the sample from North Wales and 14% from Leicestershire. However, there may have been nurses who were undertaking graduate and post-graduate courses at the time of data collection, and who had not completed the course, thus being excluded from these figures.

Although level and type of qualification were included as independent variables that might have an effect on ability to discuss donation, caution must be taken when evaluating the significance of any associations that might be found, due to the small numbers involved. Response bias is an important factor to consider when interpreting these results. When small numbers are analysed, the risk of erroneous results and, consequently, reaching incorrect conclusions, increases.

### **Clinical grading**

The clinical grade distribution, of the respondents, is presented in Table 5.2.

**Table 5.2: Clinical Grade of respondents compared with sample population**

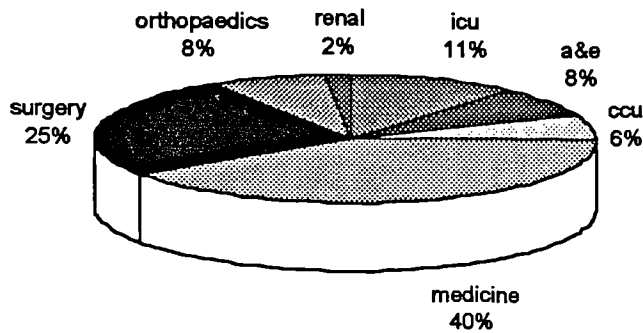
<b>Grade</b>	<b>North Wales Stratification % (n = 373)</b>	<b>North Wales Actual % (n = 166)</b>	<b>Leicestershire Stratification % (n = 403)</b>	<b>Leicestershire Actual % (n = 166)</b>
D	38.4	41.7	54.1	44.2
E	41.6	34.4	27.4	30.1
F	5.6	12.3	10.6	14.1
G	12.2	8.6	7.7	7.4
H	1.8	0.6	0.2	1.8
I	0.4	0.6	0	0

The figures reveal that the actual sample differs from the sample population. For example, after stratification, the 'D' grade percentage distribution for North Wales was found to be 38.4%, whilst in the final sample the percentage was higher (41.7%). Therefore, in North Wales, more of the 'D'-grades and fewer of the 'E'-grades returned questionnaires, whilst in Leicestershire the opposite trend was observed. In both health regions, more than expected 'F'-grade nurses responded. In North Wales, less 'G'-grades, than expected, returned completed questionnaires. The variations noted in Table 5.2, may affect the results obtained when this variable, and others, were subjected to inferential analysis. Interpretation of any findings must be made with caution.

### **Clinical Area**

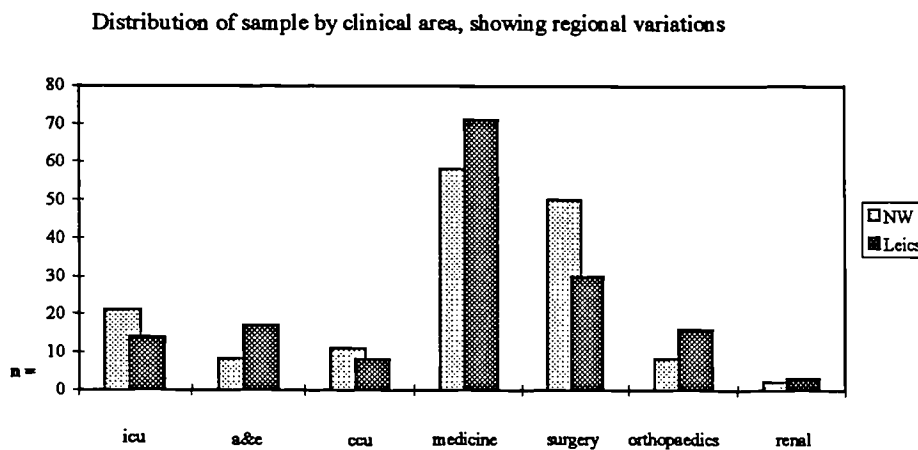
The respondents' areas of work included the main clinical settings where adult deaths occur as displayed in Figure 5.3.

**Figure 5.3: Sample showing clinical area of work**



The regional distribution of clinical areas, within the two regions, is represented in Figure 5.4.

**Figure 5.4: Clinical area of sample, showing regional variations.**



It was necessary to combine some categories because of the small numbers contained in these individual groups, to facilitate inferential analysis. For example, 'renal' merged with 'medicine'. The categories of 'medicine' and 'surgery' contain a variety of specialist areas that are normally found within the

general hospital setting such as 'haematology'; 'oncology'; 'urology'; 'ophthalmology'; 'gynaecology'; 'gastroenterology'; and 'ENT' (ear, nose and throat).

No attempts were made to control for the distribution of clinical areas among the sample. Figure 5.4 reveals that, in general, the sample numbers in the clinical areas differed only slightly. The main difference was in the surgical wards sampled. A greater proportion of nurses in the surgical areas in North Wales, responded than in Leicestershire.

Details of a further demographic variable, 'religious affiliation', will be described now. Earlier research suggested that religious beliefs may play a part in influencing the way individuals respond to death-related issues (Cleveland, 1975b; Exley et al., 1996; Foy, 1990; Youngner, 1992). It was pertinent, therefore, to include religious affiliation, within the questionnaire, to investigate the influence of this variable on nurses' donation-related behaviour.

### **Religious Affiliation**

Overall, the sample was reported to have predominantly Protestant affiliations (53.2%, n = 169), although 26.7% (n = 85) indicated that they were agnostic. Almost 15% (n = 47) allied themselves to the Roman Catholic Church, whilst the remainder (5.3%) included religions such as Methodist, Muslim, Hindu and Jewish. Respondents from North Wales reported higher numbers affiliated to the Methodist religion than those in Leicestershire: 6.1% (n = 10) for North Wales yet only 1.2% (n = 2) for Leicestershire.

Religious affiliation appears to reflect, quite closely, cultural influences in the sample. North Wales has a strong Welsh Methodist history and in many parts of this region, Welsh is the first language for many of the population. Leicestershire

has a much higher proportion of cultural diversity than North Wales and almost all of the Muslim, Hindu and Jewish religions reported could be attributed to Leicestershire.

## Attitudinal findings

The attitude scores were measured using a 46 item scale, comprising of 23 positive attitude items and 23 negative items. The scores for each of the items, within the scales, were summated and a total score obtained. Thus, on each scale, the maximum score was 138, whilst the minimum was 23. The scores for the sample as a whole were computed and the figures are presented in Table 5.3.

<b>Positive scores</b>	Mean = 90.8	Range = 108	Min = 23	Max. = 131
	Median = 91.5	Mode = 94	N = 326	
<b>Negative scores</b>	Mean = 49.5	Range = 96	Min = 24	Max. = 120
	Median = 48	Mode = 51	N = 326	

These figures indicate relatively strong positive attitudes towards organ donation and transplantation, and weak negative attitudes among the sample as a whole. Regional variations in attitude strength emerged when the sample was divide into two regional sub-samples. These findings will be presented now.

## Regional variations in attitude scores

Examination of the sub-sample attitudinal data, revealed differences in both positive and negative dimensions. (See Table 5.4)

	<b>Positive</b>		<b>Negative</b>	
	<b>N. Wales</b>	<b>Leics.</b>	<b>N. Wales</b>	<b>Leics.</b>
Mean	91.5	90.1	49	49.8
Median	92	91	48	48
Mode	89 + 95	90 + 94	36 + 46	51
S.E	1.08	1.09	1.07	1.1
S.D	13.8	14.0	13.7	14.1
Range	94	94	96	74
Min.	37	23	24	25
Max.	131	117	126	99
N =	166	166	166	166

The North Wales sub-sample was found to have slightly greater mean, median and modal positive attitude scores than Leicestershire. Multiple modes, for positive scores, were noted in both sub-samples. The range of scores for positive dimension of the two groups was identical. However, the minimum's and maximums differed, with those of Leicestershire being lower than North Wales. The negative dimension data indicated that the Leicestershire sub-sample had slightly greater mean and modal scores, than North Wales. Medians were identical. The ranges for the negative dimension showed that Leicestershire had less diversity of scores than North Wales.

Thus, the variations between the positive and negative attitude dimensions, of the two sub-samples, were slight. This similarity, therefore, appears to reject one of the initial propositions, that attitudinal influences may be contributing to the relatively low donation figures in North Wales.

The scores were later grouped to reflect the strength of positive and negative attitudes. Nine possible groups were created, ranging from high positive/low negative attitudes through medium positive/ medium negative to low positive/high negative attitudes towards donation and transplantation (see Table 5.5).

**Table 5.5: Positive and negative attitudinal groups**

Attitudes	frequency	%
high positive/high negative	1	0.3
high positive/medium negative	7	2.1
high positive/low negative	64	19.6
medium positive/high negative	0	0
medium positive/medium negative	53	16.3
medium positive/low negative	197	60.4
low positive/high negative	0	0
low positive/medium negative	4	1.2
low positive/low negative	0	0
Total	326	100

Table 5.5 reveals that the majority of respondents were found to have medium strength positive attitudes, balanced with low negative attitudes to organ donation and transplantation. This supports the ambivalence noted in an earlier study of nurses' attitudes to donation (Kent and Owens, 1995; Kent, 1991). No respondents were noted as having medium positive/high negative, low positive/high negative, or low positive/low negative attitudes.

The literature reviewed in Chapters One & Two implied that the cognitive component of attitude exerts an influence on behaviour. Written comments, made by respondents, implicated lack of knowledge and skills as reasons for not being able to discuss donation. Therefore, analyses of the knowledge-specific data was undertaken to isolate aspects the donation process, where knowledge was found to be poor, and identify any issues giving cause for concern. These, in conjunction with the issues that have arisen from the attitudinal data, were used to generate the content of the interview guide for the subsequent qualitative study. The knowledge findings will now be presented.



## Knowledge findings

Knowledge was assessed using the Organ Donation and Transplantation Attitude and Knowledge scale, which included 18 questions, designed to assess knowledge of the donation process and general transplant issues. Two points were awarded for correct responses, and one point for each incorrect answer. These were summated to obtain the total scores for each respondent. Higher knowledge scores reflected more correct answers to questions. The summated total was used to assess the degree of association between knowledge scores and ability to discuss donation.

### Overview of knowledge levels

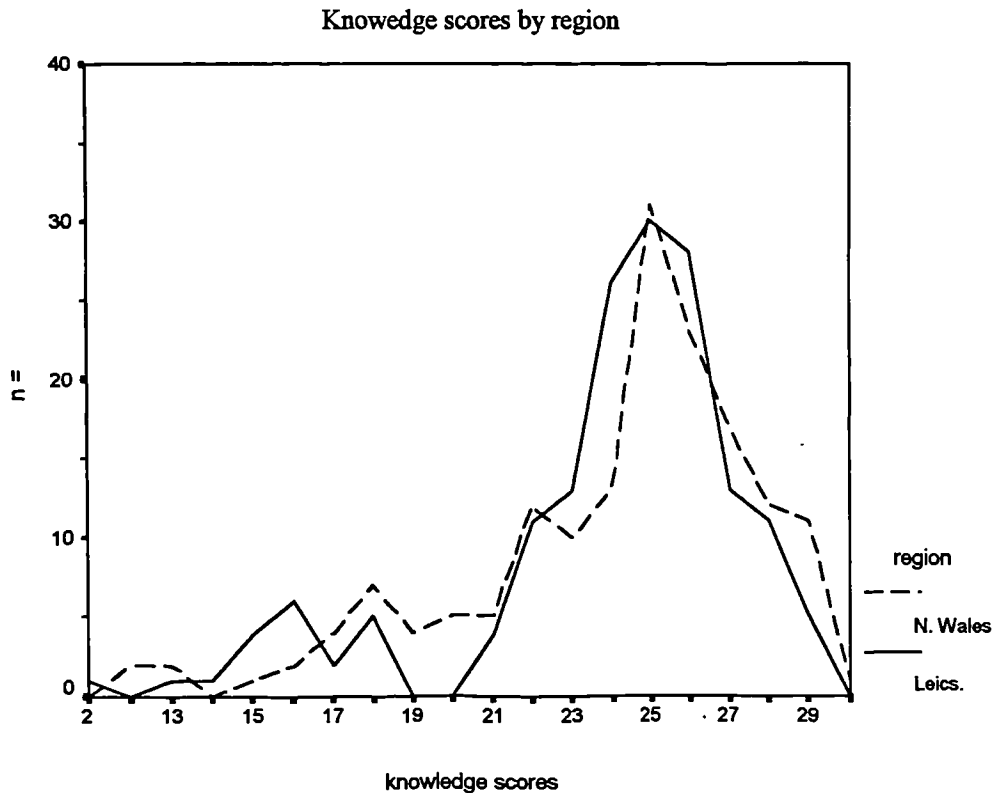
Overall, knowledge scores were not high (see table 5.6), considering that the maximum achievable score was 36. The mean was 24 with virtually no regional variation.

	<b>Total</b>	<b>North Wales</b>	<b>Leicestershire</b>
Mean	24	24.	23.9
Median	25	25	25
Mode	25	25	25
SD	3.78	3.75	3.83
Range	29	19	27
Min.	2	12	2
Max.	31	31	29
n =	323	162	161

There was little variation in any of the scores from the two sub-samples, with the median and mode located within the mid-twenties region. The range of scores from the Leicestershire sub-sample was greater than that from North Wales. However, the picture is skewed by the response from one person who, due to

non-responses, scored only 2 points. When the scores were displayed graphically, the similarities become more apparent (See Figure 5.5)

**Figure 5.5: Knowledge scores for the two regional sub-groups.**



Possible explanations for the similarity in the two sub-samples' knowledge scores are now proposed. Firstly, it could reflect the educational input on donation issues among the two sub-samples. In North Wales, it is only in the last two years that issues, concerning organ donation and transplantation, have been included in the pre-registration curriculum. Data collection for Study One commenced before this time. Therefore, it is unlikely that the nurses, in the sample from North Wales, had experienced any formal education, on this subject, during their initial nurse training. However, they may well have attended occasional study days held locally. It seems likely, from these results, that a similar scenario existed in Leicestershire. This remains, however, purely supposition.

A second explanation concerns the less formal education generally provided by the transplant co-ordinators. Locally held events may well have covered similar issues or have targeted similar groups of nurses in both regions. Discussions held with the co-ordinators, in each region, implied that this supposition was, in all likelihood, correct. In the past, these educational events have targeted the intensive care units, thereby excluding the nurses working in areas where potential organ donors are rarely identified. Thus a relationship between place of work and knowledge scores is implied. Findings relating to this, and to other factors, were explored to determine the extent of any association with knowledge scores (see Table 5.7).

Variable	Overall		North Wales		Leicestershire	
	$r_s$	(n=)	$r_s$	(n=)	$r_s$	(n=)
Place of work	.061	(316)	.124	(157)	.0133	(159)
Clinical Grade	.183***	(318)	.212**	(159)	.152	(159)
Age	.016	(279)	.032	(139)	.097	(140)

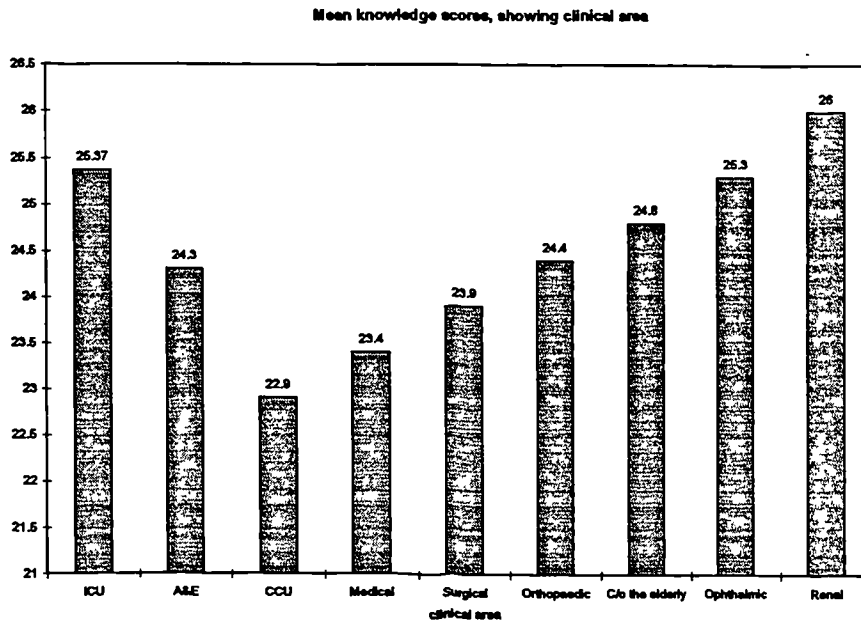
\*\*  $p < .01$       \*\*\*  $p = .001$

These results will be discussed next.

### **The effect of place of work on knowledge scores**

Nurses working in the critical care areas, such as ICU, A&E and CCU, gained higher scores than those working in the medical or surgical areas of the hospital. However, as indicated in Table 5.7, this correlation was not statistically significant. It seems more likely that the slightly stronger correlation, noted in the North Wales data, reflects the greater response from the ICU staff in North Wales compared to that of Leicestershire.

Closer exploration of responses from nurses working in each of the clinical areas revealed clear variations in knowledge levels (see Fig. 5.6).

**Figure 5.6: Knowledge scores by clinical area.**

Overall, the results revealed that 65% ( $n = 23$ ) of the respondents from the ICUs, and 60% ( $n = 5$ ) of the renal unit nurses, scored at least 26 points. The other areas had between 16% and 40% of their staff achieving the score of 26 or above. The higher scores might reflect the knowledge and expertise that develops when nurses are involved in specialist care. The delivery of high standards of specialist nursing care requires the nurse to have a good level of knowledge achieved, in part, by attendance at study days or specialist courses.

### **The association between knowledge and grade of nurse**

The figures presented in Table 5.7 suggest a weak association between knowledge scores and the grade of the nurse. Closer examination of the knowledge scores and the grade of nurse revealed that, in Leicestershire, G grade nurses' knowledge scores and ability to discuss donation were positively correlated (see Table 5.8). Weaker but still significant correlations were also noted, in North Wales' data, for the grades E and G.

**Table 5.8: Correlation between knowledge and perceptions of ability to discuss donation issues, showing regional and grade variations.**

Clinical Grade	North Wales		Leicestershire	
	$r_s$	(n =)	$r_s$	(n =)
D	.004	(68)	.02	(70)
E	.319*	(56)	.222	(49)
F	.03	(19)	.029	(22)
G	.27**	(13)	.6***	(11)
* p < .05	** p < .01		*** p = .001	

It was not possible to compute correlations for the 'H'-grade nurses, because of the small number involved. However, the knowledge responses were explored further to increase understanding of the specific factors that may be having an affect upon participation in donor identification and donation discussion stages of the organ donation process. Consequently, it was possible to identify areas of good, and poor, knowledge within the responses from both health regions. These will be presented now, beginning with the aspects of donation for which respondents scored well.

### Areas of good knowledge

There were several aspects of organ donation, and transplantation, which generated high scores, implying a good grasp of the subject (see Table 5.9).

**Table 5.9: High scoring topics, showing regional variations.**

Topic	North Wales % correct (n =)	Leicestershire % Correct (n =)
Diversity of transplantable organs	95% (155)	92% (150)
Payment for donation is illegal	95.6% (153)	93.8% (149)
Awareness of procedures for determining brain stem death	90.7% (146)	94.3% (150)
Time of death	62% (98)	68.6% (109)
Religious objections to donation	66.5% (107)	50% (80)

These included knowledge of the organs that can be transplanted, the issue of payment for donations and procedures for determining brain stem death, details of which will be discussed next.

### **Understanding of the diversity of organs that can be transplanted.**

There was minimal variation in the proportions of correct responses between the two regions and, overall, almost 94% of the sample answered this correctly. There are a number of organs, other than the heart, liver and the kidneys, that are frequently transplanted. These include the lungs, pancreas, heart valves and corneas.

### **Payment for donations**

In the UK, payment to the relatives of the donor following the donation of organs or tissue for transplantation is illegal. Almost 93% (n = 302) of respondents answered this question correctly. However there was less certainty when asked about the legality of the sale of a kidney by an individual. Correct responses in both regions fell to 76% (n = 251).

### **Procedures determining brain stem death**

There was a high level of agreement on the issue of brain stem death testing. Respondents were asked to indicate if they thought that the procedure for determining brain stem death was well established. Just over 90% of the sample correctly agreed with the statement.

## **Timing of death**

Respondents' understanding of the procedures to determine, and time, death as well as their understanding of the donation process, were assessed. A large proportion of the sample (63%, n = 207) indicated that asystole is not a prerequisite for death, thereby accepting the brain stem definition of death. However, the findings also revealed that a large minority answered incorrectly, or felt unable to reach any conclusions about the timing of death.

## **Religious objections to donation**

Variations in knowledge, related to the support given to donation by the various religious groups in the UK, were noted. More respondents from North Wales were aware that none of the major religions in the UK object to donation of organs after death. This difference, in the sub-samples' correct responses, was statistically significant ( $\chi^2 = 8.27$ ,  $p = .002$ ). The finding was unexpected, given the wide diversity of religious groups in Leicestershire compared with North Wales.

The data also revealed the areas of the donation process where knowledge levels were poor, or mediocre, as reflected in the low percentage of correct answers. These will be described now.

## **Areas of poor knowledge**

The main areas of poor knowledge have been summarised, and are presented in Table 5.10.

**Table 5.10: Low scoring topics, showing regional variations.**

Topic	North Wales % correct (n =)	Leicestershire % Correct (n =)
Exclusion criteria for organ donation	11.8% (18)	4.5% (7)
Exclusion criteria for tissue donation	13% (21)	5.1% (8)
The law and requesting donation	43.6% (70)	45.6% (73)
Impartiality of medical staff	47.7% (74)	41% (64)

These results will be discussed in more detail next.

### Knowledge of exclusion criteria for organ and tissue donation

Knowledge of the criteria for organ and tissue donation was particularly poor. Only 8% (n = 25) of the sample correctly identified all of the factors that absolutely rule out organ donation (HIV infection, septicaemia, prolonged hypotension and cancer). Similarly, only 9% (n = 29) of the sample correctly identified the criterion that absolutely rules out tissue donation (HIV infection). There was a significant difference between these responses to tissue exclusion criteria ( $\chi^2 = 6.145$ ,  $p = .013$ ), and to organ donor exclusion criteria ( $\chi^2 = 5.42$ ,  $p = .019$ ). Clearly some of the criteria were more easily excluded than others (see Tables 5.11 and 5.12).

**Table 5.11: Responses to the tissue donation exclusion criteria**

Criteria	North Wales (n = 161) <sup>1</sup>		Leicestershire (n = 158) <sup>1</sup>	
	yes	no	yes	no
Age 50+	7 (4.3%)	<u>153 (93.9%)</u>	5 (3.1%)	<u>152 (93.3)</u>
HIV Infection	<u>159 (97.5%)</u>	1 (.6%)	<u>154 (94.5)</u>	3 (1.8%)
Septicaemia	104 (63.8%)	<u>56 (34.4%)</u>	112 (68.7%)	<u>45 (27.6%)</u>
Coroner's case	74 (45.4%)	<u>86 (52.3%)</u>	97 (59.5%)	<u>60 (36.8%)</u>
Prolonged ↓BP	41 (25.2%)	<u>119 (73%)</u>	37 (22.7%)	<u>120 (73.6)</u>
Cancer	81 (49.7%)	<u>79 (48.5%)</u>	92 (56.4%)	<u>65 (39.9%)</u>

(correct answers underlined)

<sup>1</sup> where the number of respondents reported in the table do not add up to the total, the missing figures represent those who did not answer the individual part of the question.



**Table 5.12: responses to organ donation exclusion criteria**

Criteria	North Wales (n =153) <sup>1</sup>		Leicestershire (n = 155) <sup>1</sup>	
	yes	no	yes	no
Age 50+	12 (7.4%)	<u>133 (81.6%)</u>	9 (5.5%)	<u>145 (89)</u>
HIV Infection	<u>142 (87.1%)</u>	3 (1.8%)	<u>154 (94.5)</u>	1 (.6%)
Septicaemia	<u>98 (60.1%)</u>	47 (28.8%)	<u>110 (67.5%)</u>	44 (27%)
Coroner's case	72 (44.2%)	<u>73 (44.8%)</u>	96 (58.9%)	<u>58 (35.6%)</u>
Prolonged ↓BP	<u>54 (33.1%)</u>	91 (55.8%)	<u>48 (29.4%)</u>	106 (65)
Cancer	<u>88 (54%)</u>	57 (35%)	<u>111 (68.1%)</u>	43 (26.4%)

(correct answers underlined).

<sup>1</sup> where the number of respondents reported in the table do not add up to the total, the missing figures represent those who did not answer the individual part of the question.

The correct responses to each exclusion criterion were subjected to analysis, using Chi-Square test, to determine the significance of any regional differences. Only one relating to the tissue donation criteria (coroner's cases) and two relating to organ donation exclusion criteria (coroner's cases, and cancer) were found to be significantly different at the 5% level of probability. These will be discussed now, beginning with coroners' cases as an exclusion criterion.

### **Coroners cases and the donation of organs and tissue**

Coroner's cases appear to cause some confusion among respondents. Almost 60% of the respondents from Leicestershire answered incorrectly, that such cases could not donate tissue, a finding that was significantly different to that from North Wales ( $\chi^2 = 7.69$ ,  $p = .005$ ). Similar findings were noted for organ donation ( $\chi^2 = 4.89$ ,  $p = .02$ ).

The Coroner's permission, for the removal of organs, is normally sought prior to the formal request being made to the family of the potential donor. Many of the patients, who are considered as potential organ donors, need to be referred to the Coroner before a death certificate can be released. Discussions with the

transplant co-ordinators, in Leicestershire, indicated that the procedure for seeking Coroner's permission is no different, there, to elsewhere in the UK. Coroners' cases are not excluded from donation unless the Coroner refuses to give permission. If a post-mortem examination is required, it may be possible for tissue to be removed during the procedure, thus ensuring that delays in releasing the body for burial or cremation are kept to a minimum. Uncertainty about the role of the Coroner, when a patient is being considered for tissue or organ donation potential, needs addressing by educators involved in updating and informing health professionals.

### **Cancer as an exclusion criteria for donation**

Leicestershire respondents appear, from Table 5.12, to be better informed on this issue than those from North Wales. Any evidence of malignancy, with the exception of a primary cerebral tumour, always excludes the patient from being considered as a potential organ donor. The difference in responses was found to be statistically significant ( $\chi^2 = 6.23$ ,  $p = .012$ ). Cancer, however, is not an exclusion criterion for tissue donation.

The data presented thus far provides insight into the profile of the sample. This is further enhanced by the responses that focused on the incidence of assessment of donor potential in clinical areas. Since such assessment is an essential precursor to donation discussion, it was appropriate to include questions related to this issue in the questionnaire. This data will be presented next.

## **Assessment of donor potential**

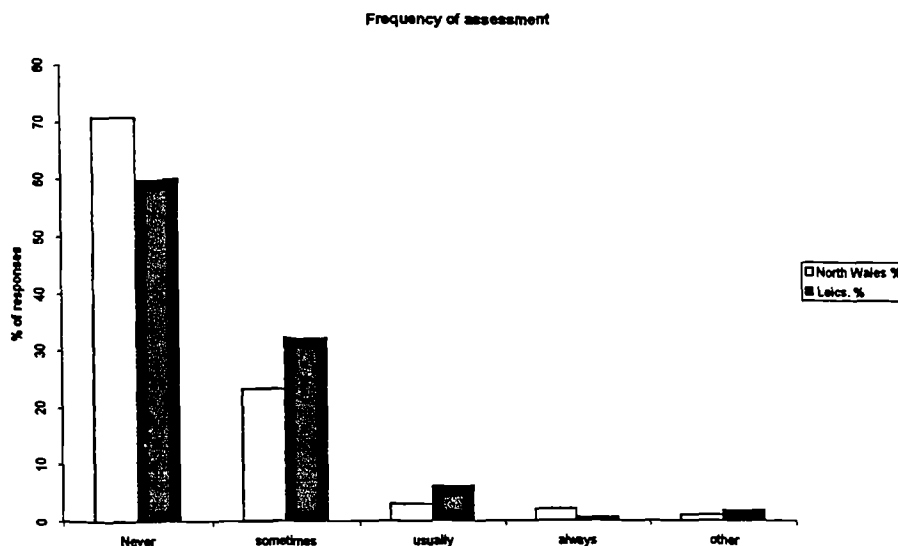
Potential donors have to be identified before the donation process can proceed. It is important, therefore, that the incidence of donor identification is ascertained.

Incorporated into the questionnaire were three questions. The first, of these, asked respondents about the frequency with which deceased patients are assessed for organ donor potential. The remaining two questions focused on the use, and efficacy, of protocols within the hospital setting to guide health professionals through the procedure for potential donor identification.

## Frequency of assessment for donor potential in clinical areas

63% (n = 205) of nurses indicated that their patients are never assessed for donor potential. A further 27% (n = 88) responded that assessment sometimes takes place, thereby accounting for 90% (n = 293) of respondents. Only 18 nurses (5.5%) indicated that assessment usually, or always, occurs. Regional variations in responses were noted (see Figure 5.7)

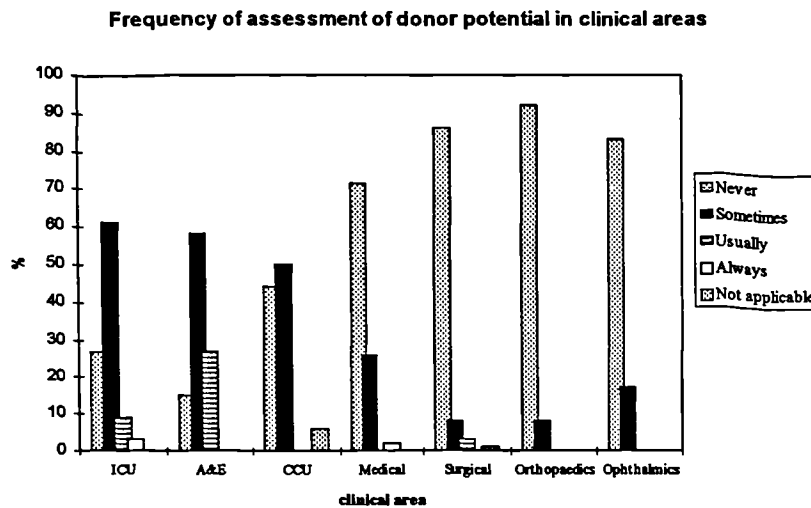
**Figure 5.7: Frequency of assessment for donor potential, showing regional variations.**



Variations were also noted when the respondents' clinical area of work was examined. Areas of the hospital that have less experience of donation, or

transplantation, were also the areas that indicated that assessment is unusual (see Figure 5.8).

**Figure 5.8: Frequency of assessment in clinical areas.**



Most commonly, it is the critical care areas where potential donors are cared for, such as ICU. Transplantation surgery will only take place in specialist areas of some hospitals. Therefore, it is inevitable that some clinical areas have a greater exposure to these events. However, regional variations were also noted, some of which were anticipated. More nurses working in the medical areas, of the hospitals in North Wales, indicated that assessment never takes place, when compared with their counterparts in Leicestershire. This was unexpected because care was taken to ensure that all of the ICUs focused on general, as opposed to specialist, cases. None specialised in neurosurgery, for example. Such specialism would have introduced bias, because specialist ICUs would expect to experience a far greater incidence of head-injured patients each year, than the general units. However, this difference was not statistically significant.

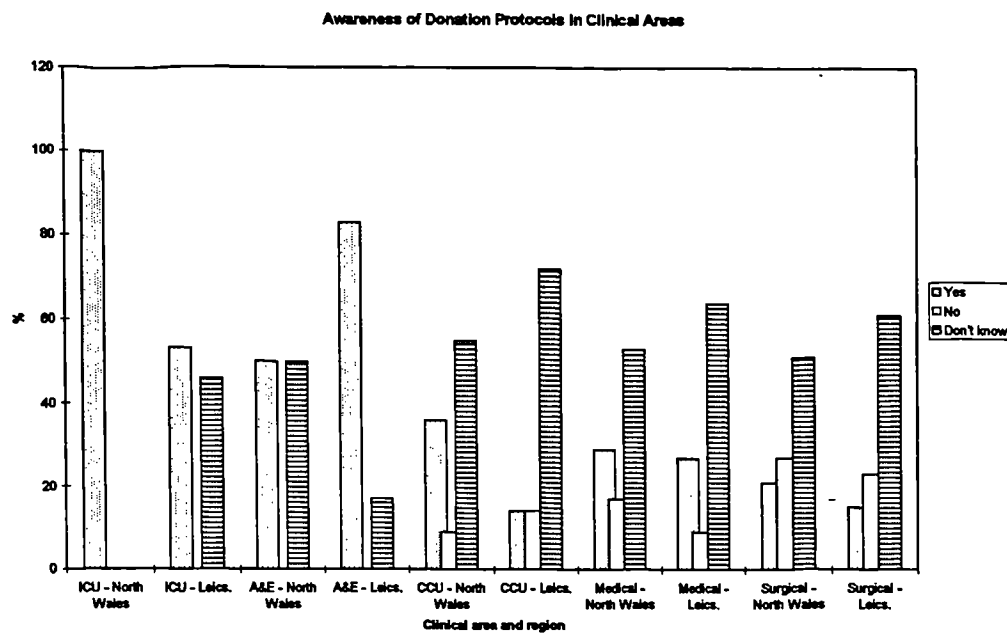
ICUs generally appeared to adopt a more proactive approach to assessment of donor potential, than the medical and surgical areas. 75% (n = 6) of respondents

working in A&E departments in North Wales, suggested that deceased patients were sometimes assessed for donor potential. However, in Leicestershire, the incidence of assessment was higher, with 38% (n = 7) of the nurses indicating that patients were usually assessed, and 50% (n = 9) 'sometimes'. In Leicestershire, patients declared dead, after admission to the A&E department, tend to be assessed for their donor potential, because a system of asystolic kidney retrieval operates in that area. However, in North Wales, the A&E departments are geographically unsuitable for this system, therefore, assessment of donor potential is restricted to tissue. The low assessment figures from this region suggest that the factors motivating tissue donation vary from those underpinning organ donation.

Very few nurses indicated that assessment takes place any more than infrequently. During the preparation stages of this research project, discussions were held with several transplant co-ordinators who suggested that protocols, to guide potential donor assessment, were being introduced into clinical areas. The aim of this initiative was to improve the frequency of such assessments. Enquiries, related to the efficacy of these protocols, were included in the questionnaire and the results are presented now.

## **Protocols and potential donor assessment**

Awareness of written protocols for organ and tissue donation varied widely among the respondents (see Fig. 5.9).

**Figure 5.9: Nurses' awareness of protocols for organ and tissue donation**

34.7% (n = 109) of respondents indicated knowledge of their existence.

However, 52% (n = 162) did not know if the hospital or the ward had protocols to help health professionals deal with organ or tissue donation. The differences, between the responses from the two sub-samples were not statistically analysed for differences, due to the small numbers of respondents in some of the clinical areas, which would have rendered Chi-Square testing inaccurate. However, the apparently high levels of awareness of the existence of the donation protocols, among the ICU nurses in North Wales, is notable and may reflect the level of educational input by the transplant co-ordinator. Awareness of protocols, among respondents in CCUs, medical, and surgical areas that, reportedly, have less contact with the transplant co-ordinator, in contrast with the ICU, is much lower.

The responses to the protocol questions were analysed further, to determine if protocols did influence frequency of assessment for potential donor suitability. These results are presented now.

## The influence of protocols on frequency of assessment for donation potential

There was evidence of a weak positive association between knowledge of the presence of a protocol and the frequency of assessment of deceased patients, the strength of this relationship being greater in Leicestershire than North Wales

(N. Wales:  $r_s = .2675$ ,  $p = .001$ ,  $n = 161$ ; Leics.:  $r_s = .3095$ ,  $p < .0001$ ,  $n = 158$ ).

These results suggest that, where awareness is low, or where protocols have not been written, assessment for donation potential is less likely.

Where protocols do exist, and awareness of their existence is high, 46% ( $n = 94$ ) of the sample reported that they provide adequate guidance for the medical and nursing staff using them. However, these figures also indicate that over half (54%,  $n = 110$ ), expressed dissatisfaction with the level of guidance provided by the donation protocols. Given this dissatisfaction, protocols and guidance are identified as issues that require further investigation. The correlation between protocols and frequency of assessment should be re-examined, using another sample, to verify the association. It would also be useful to elicit why staff perceive the protocols to be of little use in guiding practice, in areas other than ICU, or A&E. The case for such an enquiry is strengthened, further, by the apparent association between responses indicating favourable views on level of guidance provided by the protocols, and increased frequency of assessment of deceased patients for donation potential.

(N. Wales:  $r_s = .2714$ ,  $p = .004$ ,  $n = 113$ ; Leics.:  $r_s = .2677$ ,  $p = .01$ ,  $n = 92$ ).

To contextualise the data related to assessment of potential donors, respondents were asked to comment on their experience of the donation process. The findings pertaining to this issue will be presented now.

## Previous experience of donation

Experiences of caring for patients, who became organ or tissue donors, were well reported (44%; n = 144). The incidence of donation experience differed significantly when the data from the two regional sub-samples were examined ( $\chi^2 = 5.29$ ,  $p = .02$ ). Reported previous experience was higher among respondents in North Wales (51%, n = 83) than Leicestershire (37%, n = 61).

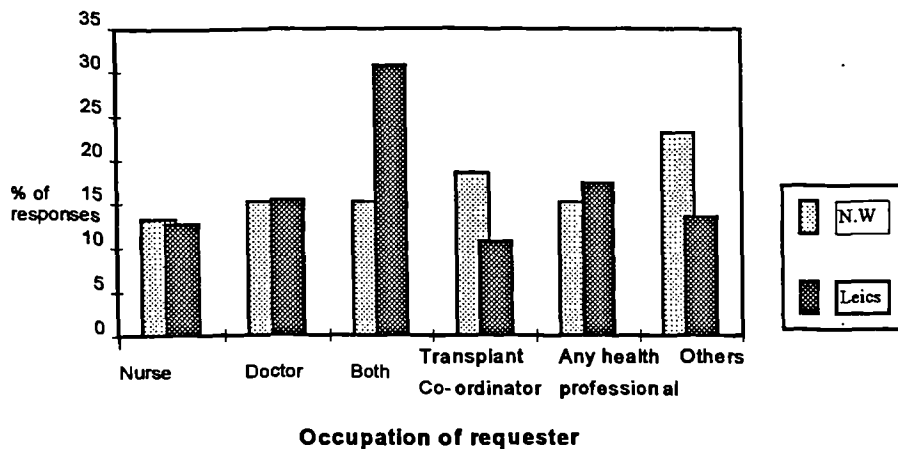
Very few sample members, however, indicated previous participation in the discussion stage of the donation process (11%; n = 36) and no regional differences were noted. In light of these findings, data appertaining to whether or not nurses should be participating in this stage of the donation process will be presented next.

## Who should ask about donation?

The most appropriate person to ask about donation intentions, according to respondents, ranged from the nurse who is caring for the potential donor and the family (12%, n = 39), to the family doctor (1%, n = 2). The main categories of responses are displayed in Figure 5.10.

A team approach was favoured by respondents, with 21% (n = 69) indicating that the task was best carried out by a doctor and nurse, thereby optimising professional attributes. Others indicated that they thought that it should be the job for a specially trained nurse (5%, n = 17), an experienced unspecified health professional (16%, n = 51) or a transplant co-ordinator (13%, n = 44), who is, coincidentally, often a nurse.



**Figure 5.10: Who is the most appropriate person to discuss donation?**

Both regional sub-samples considered clinically based health professionals to be the most appropriate person: 92.8% (n = 141) of North Wales' respondents and 90.7% (n = 136) in Leicestershire. The transplant co-ordinator was identified by 18.4% (n = 28) of respondents from North Wales, and 10.7% (n = 16) from Leicestershire. These findings reflect respondents' views rather than actual observations of persons carrying out this request role. Therefore, one can only speculate about the reasoning for these findings. After speaking with the transplant co-ordinators in both regions, these findings appear to highlight the lack of standardisation in transplant co-ordinator involvement in the donation process. Some co-ordinators like to become involved relatively early in the process, and are available to support health professionals during the request stage. Others favour later involvement possibly due to concern at being seen to influence the decisions made by the relatives of the potential donor.

Other people that were mentioned by respondents included the family doctor (only identified among Leicestershire data); personnel involved with transplantation, such as the potential recipient and the transplant surgeon (both regions); any experienced health professional, not one that is necessarily clinically-based (both regions); and a multi-disciplinary team (both regions). A

small number of respondents, from both regional sub-groups, commented that the decision pertaining to the most appropriate person to ask about donation, should be made by considering the specific circumstances at the time.

Opportunity for comments was provided: 125 respondents commented on their choice of requester. These focused on the qualities or attributes, of the person who discusses this sensitive issue, when considering who should be assigned to carry out this task. Nurses were seen to be a valuable member of the requesting team because they were better known to the family, and were believed to possess better communication skills than the doctor. They were also thought to have more empathy with distressed relatives. Almost 30% (n = 37) identified being known to the family as an important determinant. Trust went alongside this familiarity, the aim being that the family would feel more at ease at an emotional and distressing time in their lives. The need to offer support to family members, by nursing staff who had been caring for the potential donor, also featured among the nurses' comments. This emphasis on caring for the family's needs, is demonstrated by the following statement given by a Staff Nurse who worked in an Accident and Emergency department:

*“ Where possible it would be nice for the preparation of the family to be done by a very ‘kindly’ person, not an over-worked and tired medic who cannot either empathise or sympathise with the family.”*

*(A&E Staff Nurse)*

Among the 39 respondents who suggested that the nurse should be the one to make the request, there was evidence of support for nurse participation from areas where the donation process is, at present, less commonly experienced, such as medical and surgical wards. However, a large minority of the respondents (21%, n = 27), stressed the importance of being able to answer any questions that the family members might have, thus making knowledge and experience a requirement for the requester. There were doubts expressed, that the nurse working on a general ward would not have sufficient knowledge of the donation

process and, therefore, would be unable to meet this requirement. This view was reflected in the following comment made by a Staff Nurse (E-grade) working in a general surgical area:

*“I feel that the nurse should ask but with support from a transplant co-ordinator because the nursing staff need more education concerning transplantation. In general wards they (the nurses) are very rarely going to come against this problem and feel that they do not have sufficient training to approach this subject. The way they communicate with the families of potential donors might inhibit their (the families) responses.”*

*(Surgical Staff Nurse)*

It appears, therefore, that knowledge, and experience, when combined with good interpersonal skills, are perceived, by the respondents, to increase self-confidence. This, correspondingly, enhances suitability for being chosen as the person who should initiate donation discussions with the relative of the potential organ or tissue donor. A number of attributes were identified, in the respondents' comments, as key determinants for the selection of the person to discuss donation with the relatives of the potential donor (see Table 5.13).

**Table 5.13: Qualities of the person making a donation request.**

Being able to establish rapport
Being known to the relatives
Being able to establish feeling of trust
Existence of a caring & close relationship with the relatives
Empathy
Impartiality
Good level of knowledge
good interpersonal skill
Good communicator
Confidence

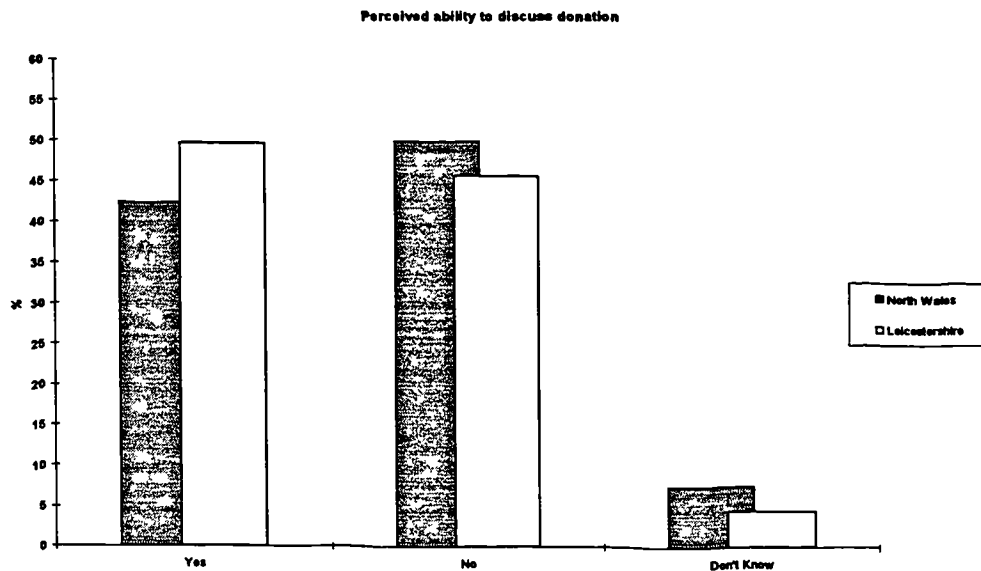
These are not occupation specific, but clearly reflect the qualities that underpin the roles assigned to nurses during the donation process which were summarised in Table 2.1.

The respondents were also asked to comment on their self-perception of ability to undertake donation discussions, which was identified as the dependent variable in this investigation. Details of the responses, to the Question 30 'Do you feel able to discuss donation?' will be presented now.

### **Do you feel personally able to approach a family for consent for organ or tissue donation?**

The respondents were asked to answer by indicating 'yes', or 'no'. Space was also given for comments. An additional category of response emerged, after a few nurses answered 'Don't know'. Overall, the results were inconclusive, with no clear picture of ability emerging. There was almost an equal split in the number of affirmative and negatives responses to this question. When the sample was divided by region, a similar pattern was noted, as can be seen in Figure 5.11.

The graph indicates that the sub-sample from North Wales appeared to have slightly less confidence in their able to undertake this behaviour, compared with the sub-sample from Leicestershire. The small number of those who did not answer ( $n = 31$ ) is notable in that it reflects the individual strength of certainty about personal abilities in this aspect of the donation process.

**Figure 5.11: Nurses' perceptions of ability to discuss donation**

The responses are illuminated by the comments of 120 respondents who gave reasons for their decision. These are summarised in Table 5.14, and are grouped under the headings able to, and unable to, discuss donation.

**Table 5.14: Perceptions of ability to discuss donation - underlying constructs.**

<b>Able to discuss donation</b>	<b>Unable to discuss donation</b>
Close caring professional relationship with relatives and patient.	Lack of skills (not defined).
Known to the family.	Lack of experience.
Good interpersonal skills	Lack of knowledge.
Something good coming out of A bad situation.	"Not my responsibility"
Wanting to meet the needs of the Patient and relatives.	Too distressing.
Professional responsibility.	Personal indecision about donation.
Good knowledge of the donation process.	

The contents of Table 5.14 provide some insight into the dilemmas facing nurses' when deciding about participation in donation related behaviour. There is evidence of conflict between professional and personal beliefs and values. For example, some indicated that ability was determined by the existence of a close, caring professional relationship, something that most nurses would strive to

attain. However, for others, it appears that this relationship may not be sufficient, for reasons that cannot be deduced from this data, and, instead, perceptions of inability to discuss donation are evoked, through feelings of inadequacy, or emotion.

Further details, of the qualitative data that generated the key points identified in Table 5.14, will be presented now.

### **The influence of experience, and skills, on nurses' perceptions of ability to discuss donation**

The majority of respondents' comments (58%;  $n = 70$ ) focused on feelings of inability to discuss donation with bereaved relatives. Of these, 34% ( $n = 24$ ) cited lack of knowledge, experience or skills as being the primary reason for not feeling able to make a request. The lack of such attributes appeared to reduce the nurse's self-confidence. There was a strong emphasis on the need for training, knowledge enhancement, which includes that of the donation process, and the development of good interpersonal skills, attributes that were also identified by those who felt able to personally participate in this phase of the donation process. Lack of skills was, however, a vague response and, consequently, was included as an item for qualitative exploration in Study Two.

Positive comments that related to ability to discuss donation focused, in general, on the concept of professional responsibility, as the following section briefly indicates.

### **Professional responsibility as a determinant for participation in donation request.**

40% ( $n = 48$ ) of the respondents' comments indicated that nurses have a professional responsibility to find out what the patient would have wanted in

relation to donation. Participation was also advocated to reduce the risk of further distress that might arise from relatives discovering the missed opportunity for donation, days, weeks or even months later.

Space for comments was limited and consequently, the details given by respondents were brief. Yet, in view of the relatively high proportions of the comments that focused on this and the previous issue related to lack of knowledge, these issues required further exploration and so were to be discussed in Study Two.

The system of donation also emerged as an issue that appeared to determine self-perceptions of ability to discuss donation, as the following section highlights.

### **The influence of ‘opting-in’, on ability to participate in donation discussion**

A small number of respondents commented that they should not have to ask about donation. The expressed feelings of resentment, that the request has to be made at all, are summed up by the following comments made by a F-grade nurse working in an ITU:

*“People should have to ‘opt-out’ - of organ donation. This way organs would be more available. There would be no moral or ethical dilemmas for all involved in the process of requesting donation. It would be an automatic process. I feel greater education of the situation is also required. The general public would be more accepting of donation if they understood what was involved in the assessment of donation potential.”*

*(ICU, Junior Sister)*

Almost 40% of the sample (n = 129) indicated that the current ‘opting-in’ system of donation should be changed to an ‘Opting-Out’ approach. A further 37% (n =

120) were uncertain about the need for change reflecting, perhaps, limited awareness of the alternatives.

Inferential analyses, undertaken on data pertaining to the system of donation (Question 59, in the Organ Donation Attitude Scales, see Appendix 6), provided clarification of the relationship between support for changes to the current system of donation in the UK, and perceived ability to discuss donation with bereaved relatives (support for a change to opting-out:  $r_s = .117$ ,  $p = .041$ ,  $n = 302$ ; support for a change to required request:  $r_s = .213$ ,  $p = .001$ ,  $n = 221$ ). These weak correlations suggest that the non-compulsory aspect of donation request, which puts the onus for deciding to approach relatives to ask about donation on the individual practitioner, may be adversely affecting nurses' behaviour in relation to donation discussion. Regional variations were noted (see Table 5.15)

**Table 5.15: Correlation between changes to the donation system and perceived ability to discuss donation.**

	Opting-out ( $r_s$ )	Required Request ( $r_s$ )
North Wales	.051 ( $p = .53$ , $n = 154$ )	.125 ( $p = .2$ , $n = 107$ )
Leics.	.171 ( $p = .037$ , $n = 148$ )	.291 ( $p = .002$ , $n = 114$ )

The figures, in Table 5.15, suggest that, in Leicestershire, a change to opting - out, or more significantly, to required-request, might positively effect the incidence of donation discussion by nurses. Required-request would place a legal requirement on health professionals, including nurses, to discuss donation with relatives, thus moving the onus away from the individual practitioner, and on to legislation. Opting-out appears to be less influential on ability to discuss donation, possibly because the system, if taken literally, eradicates the request stage from the donation process. If no objections to organ or tissue donation are expressed during life, then retrieval would be considered automatically upon death.

When the two variables, opting-out and required request, were examined for association with each other, a highly significant, but weak, correlation coefficient



was computed. This suggests that respondents, who support a change to opting-out, may be more likely to support a change to required request:

$r_s = .2867, p < .001, n = 217.$

The association was stronger in North Wales than in Leics.:

NW:  $r_s = .403, p < .001, n = 104$ ; Leics.:  $r_s = .178, p = .059, n = 113.$

However, since changes, to the donation system, are unlikely in the foreseeable future (New et al., 1994), asking for permission to remove organs and tissue for transplantation will continue to be part of the donation process. Greater understanding of factors affecting nurses' ability to participate in this process would facilitate the development of interventions intended to support health professionals in this aspect of patient care. Therefore, the attitudinal, demographic and professional data were explored further to determine the extent of influence that these have on nurses' perceptions of ability to discuss donation with relatives. The findings will be presented now.

## **The influence of personal and professional factors on self-perceptions of ability to ask for organ or tissue donation**

The personal and professional variables (including attitude, gender, age, religious affiliation, grade of nurse, qualifications, clinical area) were examined to determine the extent of association with the dependent variable, ability to discuss donation. The results of the correlation analyses are presented in Table 5.16.

**Table 5.16: Correlation between personal, professional and attitudinal variables, and self-perception of ability to discuss donation.**

Variable	North Wales		Leicestershire	
	r <sub>s</sub>	(n =)	r <sub>s</sub>	n =
Gender	.009	(160)	.04	(156)
Religious affiliation	.016	(156)	.032	(154)
Qualifications	.136	(160)	.064	(156)
Age	.196*	(139)	.044	(136)
Grade	.298****	(158)	.07	(155)
Clinical area	.248****	(157)	.119	(155)
Experience	.217**	(152)	.091	(137)
Care of donor	.239**	(161)	.07	(157)
Personal donation	.012	(161)	.136	(154)
Positive attitude	.115	(161)	.052	(157)
Negative attitude	.111	(161)	.197*	(157)
High positive/low negative	.021	(161)	.122	(157)
Fear of disfigurement	.134	(161)	.094	(155)
Fear of mutilation	.162*	(159)	.202**	(157)
fear of increasing distress	.153*	(159)	.117	(156)
Knowledge level	.139	(161)	.15	(157)
	* p < .05	** p < .01	*** p < .001	**** p < .0001

The correlations found to be significant have been marked. Caution must be taken, however, when interpreting these results because of none of these significant correlations exceeded an  $r_s$  of 0.5. However, negative attitude strength and fear of mutilation were found to correlate significantly, in the Leicestershire sub-sample. In the sample from North Wales, more variables were found to have significant correlations with ability to discuss donation. These were age, grade, clinical area, experience of donation, fear of mutilation and fear of causing distress.

Further details of these results will be presented and discussed now, beginning with those that the literature had previously identified as being possible determinant of donation behaviour, but which the present research cannot corroborate.

## **Gender, religious affiliation, qualifications and perceived ability to discuss donation**

It does not appear, from the data generated by this study, that level of education, gender, or religious affiliation have any significant association with self-perception of ability to discuss donation wishes with the relatives of the deceased, contrary to previous research findings (Parisi & Katz, 1986; Whittaker, 1990). There was great diversity of responses within these variables, and the sub-groups contained small numbers of nurses. This may, therefore, have contributed to the observed results. Sampling bias almost certainly reduced any effect by gender. The number of males in the sample was small and, consequently, masked any relationship with perceptions of ability to discuss donation. Similar reasoning can be applied to religious affiliation and qualification. Educational markers differed from those used by Parisi and Katz since, in the present research, professional and higher education were the variables being studied. In Parisi and Katz' research, the focus was on secondary and tertiary education.

## **Age and perceived ability to discuss donation**

The weak correlation with age of the nurse and the dependent variable was statistically significant among the sample group from North Wales. This suggests that, here, the perceived ability to discuss donation intentions possibly becomes more positive with age, with older nurses having greater confidence in their ability to raise this sensitive issue with the relatives of the potential donor.

## **Grade of the nurse and perceived ability to discuss donation**

A weak relationship between grade of the nurse and perceived ability to discuss donation is implicated by the findings presented in Table 5.16, suggesting that

perceptions of ability to discuss donation with the family of the potential donor become enhanced with higher grade. Again the significant correlation was only evident in the North Wales sub-sample.

### **Clinical area and perceived ability to discuss donation**

Clinical area appears to have a slight influence on perceived ability to discuss donation with relatives. Nurses working in areas such as ICU, A&E and CCU appear more likely to feel able to ask for organ donation than those nurses working in other clinical areas (see Table 5 17).

<b>Clinical Areas</b>	<b>Yes</b>	<b>No</b>	<b>Don't Know</b>
<b>ICU</b>	71% (n = 25)	29% (n = 10)	0
<b>A&amp;E</b>	60% (n = 15)	32% (n = 8)	8% (n = 2)
<b>CCU</b>	53% (n = 10)	42% (n = 8)	5% (n = 1)
<b>Medical</b>	41% (n = 51)	52% (n = 65)	7% (n = 9)
<b>Surgery</b>	45% (n = 33)	49% (n = 36)	6% (n = 4)
<b>Total</b>	48% (n = 134)	46% (n = 129)	6% (n = 16)

### **Previous experience of caring for a donor and perceived ability to discuss donation**

There was evidence of a weak correlation between previous experience of the donation process and perceived ability to discuss donation suggesting that previous experience of donation enhances self-confidence to undertake discussion of donation issues with the potential donor's family. However, experience appears to have little effect on perceptions of ability to discuss donation with the family among the sub-group from Leicestershire. It was not possible to obtain further details of these experiences, within this survey, as such

inquiries are more suited to the qualitative domain. Therefore, this was included for exploration in Study Two.

## **Personal intentions towards donation**

Personal intentions towards donation after death were also examined but were not found to correlate significantly in either sub-samples (see Table 5.16). However, the figure for Leicestershire was higher than that for North Wales, which suggests that issues other than personal donation intentions must be explored to fully understand nurses' behaviour in relation to the donation process.

The attitudinal results, summarised in Table 5.16, are presented now.

## **The influence of attitudes on self-perception of ability to discuss donation**

The scores, for both the positive and negative dimensions of attitude, were analysed for any evidence of association with perceptions of ability to discuss donation (see Table 5.16).

### **Positive attitude and perceptions of ability to discuss donation**

The variables that make up the positive dimension of attitude to organ donation and transplantation appeared to have little effect on perceptions of ability to discuss donation. The extremely weak association, found in data from North

Wales, was twice as great as that of Leicestershire. Therefore, a possible association is implied, but cannot be confirmed.

## **Negative attitude strength and perceived ability to discuss donation**

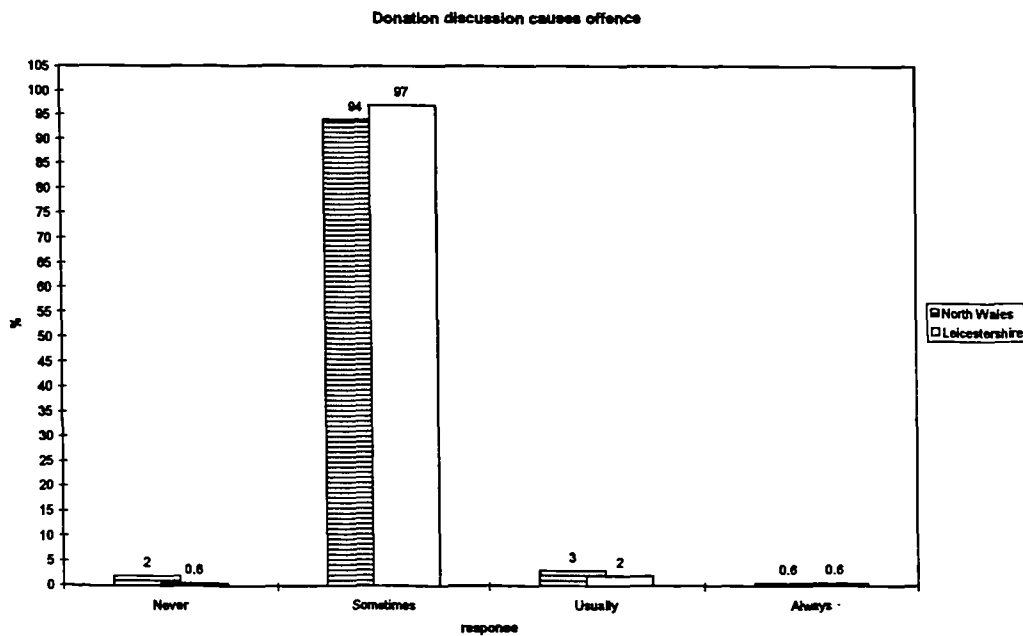
Correlation analysis, of the negative attitude dimension and ability to discuss donation, revealed a possible influence among the Leicestershire sub-sample but not in North Wales. However, the association is weak. The findings infer that, in the Leicestershire sub-sample, negative feelings about donation exert an inhibitory effect on feelings of ability to approach the family members of the potential donor and discuss donation issues with them.

Previous research studies suggests that, within the negative dimension, factors such as fear of upsetting the relatives, adding to their grief, as well as fears over possible mutilation to the body, may affect ability to make a request for donation to the deceased's relatives. These concepts are discussed now.

## **Fear of causing distress and perceived ability to discuss donation**

Concern that a request for donation would increase the relatives' distress appears to have an inhibitory effect on donation discussion, with the correlation being greater in North Wales, than Leicestershire. However the association is weak (see Table 5.16) and the significance level of the findings introduces an unacceptable risk of error. Nevertheless, a large proportion of the sample indicated that requests sometimes impose unfair strain onto the family, and can cause offence (see Figure 5.12).

**Figure 5.12: Nurses' perceptions that donation request offend the potential donor family.**



When the effect of previous experience of the donation process on distress was analysed (see Table 5.18) it emerged that, in Leicestershire, previous experiences may be generating fears that affect future behaviour. No such effect was found in the data from North Wales. This requires further investigation, and so was included for discussion in Study Two.

**Table 5.18: Correlation between previous experience and fear of causing distress**

Statement	Previous experience			
	North Wales		Leics.	
	r <sub>s</sub>	p =	r <sub>s</sub>	p =
“Requesting organ donation puts an unfair strain on families of deceased patients	.0383	.630	.1502	.059
	(n = 160)		(n = 159)	
Families will be offended if asked for organ donation	.0500	.53	.0121	.88
	(n = 161)		(n = 158)	

The second statement in Table 5.18 highlights the lack of association between fear of causing offence by asking for donation, and experience of donor care. This contradicts with previous research findings (Johnson, 1992; Pelletier, 1992; Savaria, Rovelli, and Schweizer, 1990; Sque, 1996) which suggest that experience of caring for a potential organ donor reduces the feeling that the donation request causes offence. In the present research, 93% (n = 304) of respondents agreed that offence can be caused when relatives are asked to consider donation. However, there is no corroborative evidence to indicate that these concerns would prevent discussion of donation with the family.

### **Fear of mutilation and perceived ability to discuss donation**

Table 5.16 highlighted the association between the belief that organ donation may be disrespectful to the body, and perceived ability to discuss donation with the family of the potential donor. This suggests that, those who believe that organ donation violates the body, in some way, are less likely to feel able to discuss donation with bereaved relatives. However, 46% (n = 71) of respondents from North Wales, and 38% (n = 61) from Leicestershire, felt unable to discuss donation with the family and yet disagreed that organ donation was an unwarranted violation of the body. This questions the effect of this factor on discussion behaviour.

The indeterminate nature of these findings supports the view that the reasons, behind the respondents' perceptions of ability to discuss donation, are multi-faceted and complex. To enhance understanding of this complexity, and to determine the predictive power of the variables that have previously been tested independently with ability to discuss donation, multivariate analyses were undertaken.



## The combined effect of psychosocial variables and ability to discuss donation

Age, grade, experience, and negative attitudes have already been implicated as having an independent effect upon ability to discuss donation (see Table 5.16). Additional analyses were undertaken to explore the hypothesis that these variables, when combined, enhance the likelihood of feeling able to discuss donation. Logistic Regression was used to explore this assertion, using six variables (age, grade, qualifications, previous experience, negative attitude score, and clinical area of work) to yield a predictive equation. See Table 5.19.

**Table 5.19: Logistic regression: prediction of the likelihood of the nurse feeling able to discuss donation with bereaved relatives - using psychosocial variables as predictors.**

Predictor variable	NW	Leics.	NW	Leics.	NW	Leics
	b		Wald		Odds Ratio	
Age	-.537	.009	4.38*	.12	.95	1.01
Grade	-.58	-.21	7.31**	1.04	.56	.81
Qualifications	-.18	.03	.12	.00	.83	1.04
Experience in care	.42	.28	2.55	1.41	1.53	1.32
Negative attitude	.01	.04	.22	6.33*	1.01	1.04
Clinical area	.35	.08	7.72**	.54	1.43	1.09
Constant	1.01	-2.12	.34	2.61		
-2 log likelihood	152.12	170.67				
Model Chi-Square	33.77	14.97				
p <	.0001	.05				
overall rate of correct classification	72.59%	64.18%				
n =	135	134				
*p < .05    **p < .01						

The logistic regression model for North Wales was, statistically, highly significant (Model Chi-Square = 33.77, df = 6, p < .0001). The classification results show a good level of success, with an overall classification of 72.59%.

The model of Leicestershire was less significant (with a Model Chi-Square of 14.97,  $df = 6$ ,  $p = .02$ ) yet still achieved an overall classification of 64.18%.

This process of analysis suggested that age, grade, and clinical area of work were, for the North Wales sub-sample, the three predictors that were significantly related to ability to discuss donation. The nurse who is older, holds a higher grade and who works in ICU, A&E or CCU is, statistically, more likely to feel able to discuss donation with bereaved relatives.

The results from the Leicestershire sub-sample highlighted only one significant predictor, negative attitude, to donation discussion. For these respondents, it is likely that nurses who hold strong negative attitudes to donation would feel less able, or willing, to discuss donation.

The results of the logistic regression must be interpreted with caution. The regional variations may be due to potential response bias. The profiles, of the two regional sub-samples, described earlier in this chapter, were not identical. Therefore, such variations may have influenced these results in Table 5.19. To clarify the extent to which response bias may have contributed to the results, these variables were included for further discussion with the participants of Study Two.

## **The effect of knowledge on donation discussion ability**

Total knowledge scores, together with those responses to specific donation topics, were analysed to explore the correlation with perceived ability to discuss donation. The bivariate results are summarised in Table 5.20.

Variable	North Wales		Leicestershire	
	$r_s$	(n =)	$r_s$	(n =)
Total knowledge score	.138	(161)	.149	(157)
Procedures for brain stem death testing	.135	(160)	.133	(156)
Time of death	.19*	(159)	.12	(156)
Death declared before retrieval	.149	(159)	.055	(156)
Religion support donation	.044	(160)	.145	(157)
Organ donors are usually patients declared brain stem dead	.06	(160)	.052	(156)
Medical impartiality	.044	(154)	.169*	(153)
Selling organs is illegal	.017	(161)	.072	(157)
Requests are not compulsory	.186*	(160)	.033	(157)
Diversity of transplantable organs	.089	(161)	.243**	(157)

\*  $p < .05$  \*\*  $p < .01$

Clearly, few of the variables, identified as generating high or low numbers of correct scores, appear to have an association with ability to discuss donation when Spearman's rank-order correlation was performed. Two of the correlations, arising from the North Wales sub-sample, were found to be significant. These focused on the timing of death, in relation to organ donation, and request for donation. Results, from the Leicestershire sub-sample, indicated that statistically significant associations were noted for the variables related to medical impartiality and awareness of the variety of transplantable organs. These will be discussed now.

### **Knowledge of the timing of death and perceived ability to discuss donation**

Acceptance of brain-stem death, as a definition of death, appears to increase the possibility of the nurse feeling able to discuss donation. Implicit, here, is the acceptance of asystole as being non-essential for defining death, in agreement with Pallis' (1984) definition. Greater comprehension of this concept may be associated with enhanced response to questioning by relatives, thereby helping them to accept this unconventional notion of death.

## **Knowledge of the law and perceived ability to discuss donation**

In the North Wales sub-sample, there was a weak correlation between nurses who answered correctly, that UK law does not require a request for donation to be made, and enhanced ability to discuss donation with relatives. However, reasons for this finding could not be ascertained from this survey.

## **Knowledge of medical impartiality and perceived ability to discuss donation**

The impartiality of the doctor who diagnoses brain stem death in the potential donor was assessed and the responses examined for association with self-perception of ability to discuss donation. A weak, but statistically significant correlation, was noted in the responses from the Leicestershire sub-sample. This suggests that nurses who believe, incorrectly, that the doctor who diagnoses death of an organ donor can also be involved in the removal or transplantation of the organs, are more likely to feel unable to discuss donation with the family of a potential organ donor. There is nothing, in the Study One data, to indicate why this finding should emerge in one sub-sample and not in the other, therefore, this issue requires further investigation.

## **Knowledge of types of transplants and perceived ability to discuss donation**

Knowledge of the diversity of transplants, that can currently be performed, appears to be significantly associated with enhanced perceptions of ability to discuss donation issues with relatives, although this is only evident in the responses from Leicestershire. Nurses, in Leicestershire, may have a greater

awareness of transplantation because transplant surgery is performed there, and not in North Wales.

The analysis of the knowledge data produced results that are, again, inconclusive. Several factors have been identified as possibly influencing nurses' perceptions of their ability to undertake the donation request role. However, only individual effect has been examined. Therefore, it follows that the cumulative effect of the variables, identified as having a statistically significant association with perceptions of ability to discuss donation, should be explored using multivariate logistic regression. The results of this are presented now.

### **The factors having the most influence on perceived ability to discuss donation with relatives.**

The results, so far, have indicated that a small number of psychosocial factors may exert an independent effect on feelings of ability to carry out donation discussion. These include the strength of negative attitudes; previous experience in the care of a potential donor; being personally in favour of organ donation; changes to the system of donation; awareness of the legal aspects of the donation process; knowledge of procedures used to determine brain stem death; awareness of the different types of transplantable organs and tissue; and awareness of the impartiality of medical practitioners within the donation process.

To determine any cumulative effect, logistic regression was performed using 20 predictor variables which, bivariately, were found to be significantly associated with the ability to discuss donation. The regression was calculated using the entire sample ( $n = 326$ ), and subsequently repeated with each of the sub-sample data sets (North Wales:  $n = 163$ ; Leics.:  $n = 163$ ) (see Table 5.21).

**Table 5.21: Logistic regression: prediction of likelihood of being able to discuss donation, showing overall and sub-sample results.**

Predictor Variables	b						Odds Ratio		
	Sample N. Wales Leics.	Sample N. Wales Leics.	Wald	Sample N. Wales Leics.	Sample N. Wales Leics.	Sample N. Wales Leics.			
Age	-0.4	-0.8	-0.3	2.29	3.09	41	96	92	97
Knowledge	-0.6	0.9	-2.5	84	44	3.26	94	1.09	78
Qualifications	-1.23	-2.06	-6.8	3.68	3.56	26	29	13	51
Personal donation intention	11	17	.44	21	13	1.49	1.11	1.19	1.55
Negative Attitude	0.2	0.1	0.6	2.28*	1.7	4.22*	1.02	1.01	1.06
Clinical Area	2.6	4.3	1.7	5.26	3.79	81	1.29	1.54	1.18
Religious support for donation	-1.1	7.3	-0.5	0.7	71	0.1	89	2.08	95
Organ donors usually brain stem dead	4.8	1.42	6.8	1.38	2.08	1.26	1.61	4.13	1.97
Death is not dependent on asystole	-5.7	-1.48	4.3	2.19	3.88*	36	56	23	1.53
Death is declared before organ retrieval	-0.4	-6.7	9.8	0.1	71	1.84	96	51	2.67
Medical impartiality	4.2	1.07	-2.2	9.6	1.71	0.9	1.52	2.92	80
Variety of transplantable organs/tissue	-1.19	-4.75	-1.55	1.02	0.2	1.33	30	0.1	2.11
Sale of kidneys is illegal	5.8	-8.9	1.5	1.36	7.9	3.76	1.78	4.1	4.46
No payment for donation is made to relatives	-1.05	-1.34	-6.6	1.31	5.7	2.6	35	2.6	5.2
Knowledge of law related to request	1.1	-1.32	1.43	0.8	2.63	4.34*	1.11	2.7	4.19
Well established procedures for determining b s d	-2.2	-9.6	1.0	0.8	5.4	0.1	81	3.8	1.120
Knowledge of exclusion criteria for tissue donation	5.0	-0.5	9.52	5.8	0.02	2.1	1.64	9.4	error
Knowledge of exclusion criteria for organ donation	0.5	-6.5	3.41	0.1	4.4	5.76*	1.06	5.2	30.27
Support opt-out	4.5	8.3	3.5	3.99*	3.58	1.06	1.57	2.30	1.42
Support required request.	1.7	-0.5	8.3	7.1	0.2	5.64*	1.18	9.5	2.28
Constant	5.04	16.5	-2.11	1.75	0.5	1.2			
-2 Log Likelihood	193.44	67.27	86.57						
Model Chi-square	37.06	39.36	37.08						
P	0.11	0.06	0.11						
Overall rate of correct classification	69.5%	83.1%	77.8%						

\* p < .05

For the sample as a whole, the predictive model was statistically significant ( $\chi^2 = 37.06$ ,  $p = .011$ ). For each sub-sample, again statistically significant predictive models were obtained (North Wales:  $\chi^2 = 39.36$ ,  $p = .006$ ; Leics.:  $\chi^2 = 37.08$ ,  $p = .011$ ). Taking the whole sample data set, two of the predictor variables were significantly related to the likelihood of being able to discuss donation: negative attitude, and support for a change to an opting-out system of donation.

Within the regional sub-samples, one predictor variable (knowledge that asystole is not an essential determinant of death) was statistically significant in North Wales. In Leicestershire, four variables were found to be statistically significant predictors of likelihood to feel able to participate in donation discussion. These were negative attitude; knowledge of the law on request; knowledge of the exclusion criteria for organ donation; and support for a change to a required request system of donation.

The influence exerted by changes to the system of donation used in the UK was notable. In the Leicestershire sub-sample, the nurses who were reported to be supportive of a change to a required request system, were twice as likely to feel able to discuss donation in comparison with those who did not (odds ratio = 2.28). However, in North Wales, the nurses who supported a change to opting out, were more than twice as likely to feel able to discuss donation than those who opposed the change (odds ratio = 2.3), although this was not identified as being statistically significant.

The inclusion of knowledge issues altered the picture presented when only psychological factors were included. Therefore, despite the weak correlation figures, knowledge does appear to contribute to determining future behavioural intention. The variations in the attributes of the two sub-samples may have affected the findings of Study One. The issue of response bias is important, and merits further discussion because of the implications for the validity and generalisability of the data.

## Response bias

The overriding intention when devising the sampling strategy, for this phase of the research, was to generate a sample that would be representative of the target population. However, insufficient information relating to all of the characteristics of this population inevitably meant that differences would emerge. The initial sampling frame identified clinical grade, and area of work as factors that would determine sample membership. However, extraneous variables were not controlled for during data collection. Consequently, the response of subjects, from the different clinical areas across both regions, was unpredictable.

This phase of the research was exploratory in nature, in that no attempts were being made to establish cause and effect through rigidly controlled methods. Previously unknown, or unverifiable, data appertaining to professional, demographic, attitudinal and knowledge attributes were generated through this design, to facilitate further exploration to enhance understanding. The exploratory process continued with the identified independent variables being examined to determine their relationship with perception of ability to discuss donation. The variations, found when the attributes of the sample were descriptively analysed, had not been predicted prior to the commencement of the investigation. The same can be said of the variations discovered by bivariate and multivariate analyses with the dependent variable. Response differences, in some of the attributes, such as in clinical area, grade, and age, may have exerted some influence on the significance of these findings. Consequently, caution must be taken when interpreting the results.

## Chapter summary

Despite the note of caution sounded above, the results, generated by Study One, support, in part, the relationships between concepts proposed in Ajzen's theory of planned behaviour. Attitudinal factors appear to affect perceptions of ability to



discuss donation, although the influence was primarily exerted by the variables associated with the negative dimension. These include the fear that mutilation might be a consequence of the retrieval of the organs or tissue; and concern that a request for donation would increase the distress experienced by the relatives. Such fears arise from subjective feelings, rather than objective professionalism, thereby raising questions about the efficacy of nurses undertaking the role of advocate as directed by the UKCC. Negative attitudes appear to exert an inhibitory effect suggesting that, where these fears exist, nurses are more likely to indicate that they do not feel able to begin to discuss donation intentions with either the patient before death, or the relatives, once the patient had died.

The influence of knowledge upon ability to identify potential donors and discuss donation with relatives was examined, and found to be weakly, but, statistically, significantly correlated. Certain aspects of knowledge appear to exert greater effect on the dependent variable, than others. For example, knowledge of the criteria that exclude donation, as well as other aspects of the donation process, such as the brain stem death testing, were positively correlated with ability to discuss donation. However, among the sample as a whole, knowledge of the exclusion criteria for organ and for tissue donation was poor. This appears to be an area of knowledge where further educational support is required, if greater participation in the donor identification and request stages of the donation process is to be achieved.

Study One has identified donation-related topics where there is an apparent knowledge deficit; information of which can be directed to those involved in the education of nurses and other health professionals. These topics include the support for donation by religious groups and the exclusion criteria for organ and tissue donation. There also appears to be potential problems in relation to donor identification, or not since this is a more accurate reflection of activity, according to the results of this investigation. Since donor identification is the first stage of the donation process, problems here will affect subsequent participation behaviour.

The influence of subjective norms, including societal influences was inconclusive. There was evidence of a positive correlation between previous experience of donation and ability to discuss donation. Respondents' comments identified unwillingness to take on sole responsibility for the role of requester favouring, instead, a team approach. Traditional roles and responsibilities appear to be influencing nurses' behaviour. For example, concern over accountability, and the legality of nurses' adopting the requester role, was expressed. The adoption of a team approach was thought to minimise the risks for nurses whilst, at the same time, enabling the nurses to provide support for the bereaved relatives. It was not possible to deduce the strength of feeling about maintaining traditional professional roles, or the factors that would encourage nurses to take a more active part in the donation process, from the survey data in this study.

The data relating to assessment of patients for donor patient in clinical areas was enlightening in that it provided, for the first time, tangible evidence of the low incidence of such assessment, despite the move to develop protocols to guide, and presumably encourage, such activity. At no time, during Study One, was the discussion of donation examined directly. The investigation was, by necessity, restricted to self-evaluation of assessment, and of perceptions of ability to undertake this role. The unpredictability of death, combined with resource limitations, led to a design that, unfortunately, could not include the exploration of nurses' feelings immediately before a donation request was made, and the evaluation of such reactions, following any subsequent behaviour.

The results from Study One, together with the comments given freely by respondents during this investigation, suggest that anticipatory feelings, evoked by the prospect of participation the donation process, do require further exploration. The analyses identified a number of variables that might exert an inhibitory effect on nurses' behaviour. However, none of the correlations, taken separately, were particularly strong suggesting that the presence, of one factor alone, may have little influence on behaviour. In addition, the logistic regression

analyses, calculating the effect that multiple factors might have on likelihood of being able to discuss donation, contributed minimally to further understanding of donation discussion behaviour. Clearly, further exploration is required to assess the validity of the tenuous links discovered between attitudes, subjective norms and perceived ability to participate in the donation process.

Although attention must be paid to the potential influence of response bias, Study One produced some notable, and unique, data. Far more is now known about the relationship between psychosocial factors and nurses' perceptions of ability to approach relatives and discuss donation issues with them. However, given the lack of clarity in some areas of Study One, which call for further investigation, the decision to include, in the research design, Study Two has been justified. Therefore, the results of this further phase to the investigation, which took place during late summer and early autumn in 1996, are presented in the next chapter, Chapter Six.

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## Chapter Six: The Findings of Study Two “Talking About Donation”

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### Chapter overview

In this chapter, the findings that emerged from the qualitative phase of the research project will be presented. The purpose of Study Two was to add quality, and depth, to the data generated by Study One, and to explore the more sensitive issues that could not be effectively addressed using a primarily quantitative design.

The quantitative approach was not appropriate to tease out the effect of encouraging, or inhibitory, factors on the nurse when contemplating discussion of sensitive and, possibly, taboo subjects such as the request to remove body parts after death for the purpose of transplantation into another human being. Nevertheless, the findings from Study One highlighted the complexity of the reasons behind this specific human behaviour. In order to enhance understanding of the experiences of the person undertaking activities, such as donation request, a phenomenological approach was adopted. Through a process of description and interpretation, greater insight into this complex phenomenon of nurses' behaviour related to the donation process, is gained.

## **The purpose of Study Two**

The purpose of this phase of the research was to enhance understanding of the meaning of experiences related to participation in the donation process. The perspectives to be explored included nurses who have played an active part in the process; those who might consider involvement in a favourable light and those who do not want to become actively involved in the identification and request stages of the donation process. Through the use of the philosophical principles of hermeneutic phenomenology, greater comprehension of behaviour that is, from the information that has been deduced so far, subjective and determined largely by irrational, and illogical thoughts, should be achieved.

Brief details of the sampling, together with justification for the research design, have already been presented in Chapters Three and Four. However, for completeness, and in keeping with the qualitative paradigm, further description of the research design will be provided now, beginning with formation of the final study group.

### **Formation of the study group.**

Volunteers from Study One, who provided a name and contact telephone number, were grouped according to grade, clinical area of work, and attitude group (see Table 6.1 for the grade profile of the sample). The questionnaire responses, generated by the volunteers and the non-volunteers, were compared for differences in the following variables: demographics, positive and negative attitude strengths, and perceived ability to discuss donation. Chi-square testing failed to find any significant differences ( $p < .05$ ).

<b>Grade</b>	<b>N =</b>	<b>%<sup>1</sup></b>
<b>D</b>	49	34.5
<b>E</b>	36	33.6
<b>F</b>	14	32.5
<b>G</b>	10	38.4
<b>H</b>	3	75
<b>Higher</b>	1	100
<b>Total</b>	113	34%

(<sup>1</sup> % of the total sample of the relevant grade)

Once satisfied that the volunteers' responses did not vary greatly from the non-volunteer group, the lengthy process of contacting the volunteers then began. Five names were chosen at random, from each of the identified groups, and each contacted using the telephone number provided. There had been a considerable time delay, for some of the nurses, from completion of the questionnaires to the commencement of the data collection stage, of Study Two. This led to many of the nurses being inaccessible for interview, due to home, or job, or other undefined, changed circumstances.

Those who could be contacted were asked if they still wished to be involved in this phase of the research and, if so, a date, time and location for the interview was arranged. The location of the interview, was chosen by the participant, as it was important that the person being interviewed felt comfortable, thereby facilitating greater freedom of speech. Some chose to be interviewed at their place of work, whilst the majority of the nurses decided to be interviewed in their own home. I planned to interview at least two nurses from each clinical area to explore issues that arose with one nurse working in, for example, a medical area, with another nurse working in a similar environment.

Sampling was completed when a substantial amount of data had accrued, rather than when saturation had been reached. This was due to time constraints imposed on the investigation. Nevertheless, this enabled me to produce an extensive and

strong description of the meaning and the subsequent behaviour, or behavioural intentions, emanating from that meaning, as suggested by Patton (1990).

Details of the final interviewees will be presented now to contextualise the subsequent findings.

## The Interviewees

Thirty-one nurses were interviewed during this stage of the research project. Table 6.2 shows the distribution of grade and clinical area among the nurse interviewees.

All names have been changed to protect the nurses' identity. The health region of employment has also been omitted, for similar reasons. No nurses refused to participate when approached but eight did not return telephone calls. At least twenty were either not in, when contacted for permission to interview, or were not available on the dates when the interviews were to take place, and they too had to be excluded from the study.

All of these interviews were carried out by myself and took place over a five month period during the latter half of 1996. The majority ( $n = 26$ ) of the interviews were one-to-one, but there were two group interviews. One began as one-to-one with myself, and the nurse interviewee, but we were interrupted, by a colleague of the nurse, who arrived unexpectedly at the house, and subsequently decided to participate in the interview.

**Table 6.2: The interviewees' grade and clinical area of work.**

<b>Participants</b>	<b>Grade</b>	<b>Clinical area</b>
Dee	D	ICU
Angela	E	CCU
Isobel	E	Surgery
Louise	G	A&E
Caroline	E	Medical/CCU
Sheila	G	ICU
Jeanette	F	ICU
Gail	I	Surgery
Olga	D	Medical
Sally	D	Surgery
Delia	D	Surgery
Helena	D	Surgery
Juliette	E	Medical
Peter	F	Medical
Claire	F	Medical
Audrey	F	Surgery
Sarah	A	Medical
Lisa	D	Medical
Jenny	E	Medical
Kate	D	Trauma surgery
Jennifer	D	Medical
Paula	D	ICU
Maria	E	ICU
Julia	E	ICU
Jane	D	CCU
Tracey	D	CCU
Susan	D	CCU
Julie	D	CCU
Annabel	G	A&E
Dave	E	A&E
Margaret	H	A&E



Another interview was arranged to take place in the clinical area. Upon my arrival, the nurse interviewee reported that two colleagues also wanted to participate. One was a health-care assistant and fell outside the inclusion criteria for the research. However, it would have appeared rude to exclude her, and may have affected my rapport with the other interviewees. Therefore, two qualified nurses, a health care assistant and the interviewer, took part in this interview.

The procedure for data collection will now be described to set the scene and facilitate understanding of the interview data and the subsequent findings.

## **Data collection**

Upon arrival, I spent a short period of time chatting socially with the participant to help establish some feeling of security, trust and rapport. This was particularly important because I was not known to most of the participants.

Every effort was made to ensure that barriers were not erected that would hamper any interaction between myself, and the interviewee. Therefore, I paid a great deal of attention to appearance and to other non-verbal cues that could hinder the development of trust and rapport. When I was interviewing in the nurse's home, I tended to adopt a relaxed style of dress, wearing casual clothes, but a more professional style was adopted when the interview was to be carried out in the work place.

Once I sensed that the participant felt comfortable with me, I suggested that the interview should begin. This generally meant that the interview would be an extension of the conversation that we were already having. I sought permission to use an audio-tape recorder to record the interview, to which all agreed. Reassurances were given, including reiterating the steps that would be taken to

ensure that any identity would be disguised and that no one, other than myself and, possibly, my supervisor, would listen to the recording.

The interview proceeded along the lines of a conversation, with an interview schedule being used as a reminder of the key issues to be covered. The sequencing, of these, was determined by the participant. I found, on the whole, that little prompting was required and that the participants were extremely willing to recall their experiences.

The interviews lasted, on average, three quarters of an hour. Those that were carried out in the home setting generally lasted longer than those that were carried in the work place. There were fewer distractions in the home, even though I did have to compete for attention with dogs, cats, babies and husbands! In the work place the interviews were shorter resulting from concerns about the patients' conditions and organisational issues, such as the needs of the ward.

At the end of the interview, the participants were given the opportunity to ask questions or to raise any other issues that they felt were relevant. I found that it was at this point that the participants began to ask me for information about the donation process. Some commented that they felt quite ignorant in their lack of knowledge in the area. I made every effort to answer their queries and agreed to arrange for any requested information to be sent to them. The interview needed to be a two way process and that, as the participants had been very generous in giving of their time for this research, in return I had a duty to answer their questions if I could.

Shortly after the interview had finished, once I had left the location, a short time was spent making field notes about the interview and summarising the conversation that had just taken place. I transcribed the audio-taped interviews as soon as possible after returning. These were then used, in conjunction with the field notes, during the analysis stage of the study.

## Analysis of the Interviews

In order to comprehend the meaning of the experiences recalled during the interview, it was necessary to transform the data as a precursor to interpretation. Therefore, the recorded interviews were transcribed verbatim. This process provided an overview of the experiences and views of each of the participants, enabling the key concepts to be identified, which could then be discussed, if appropriate, during subsequent interviews with other nurses.

A process of conceptual mapping was employed to make sense of the large amounts of data (Northcott, 1996). The process involved formulating a visual portrayal of the ideas, beliefs, thoughts and experiences, of the nurses, by accumulating all the ideas onto one sheet of paper. All of the interconnections, the key issues that emerged from the interview, were identified and laid out in the form of a map. Cognitive mapping became a form of thematic analysis, enabling the creation of a summary picture and consideration of meanings of the key concepts that were not immediately obvious but which emerged following analysis. The maps and the transcripts were examined to uncover any similarities or differences that could account for any subtle differences in the two sub-groups, identified by the Study One.

The main issues, arising from the transcripts, were isolated from the rest of the text and the theme identified. This process continued until all the interviews had been analysed and all of the key themes acknowledged. Attempts were made to obtain independent verification of the emergent themes and categories by subjecting three transcripts to review by two experienced researchers. However, due to time constraints on the part of the reviewers, this verification process was not completed. Nonetheless, a copy of the completed concept map was sent to the appropriate participant for their comments, particularly in relation to accuracy.

The key themes and concepts that emerged from the interviews are presented next, and illustrated by extracts from the interviewees. Few controls were imposed on the order of the precise content of the interviews. The interview schedule was used as a prompt and guide, but not to impose structure on the interview. For presentation purposes, and for clarity, the findings will be presented in relation to the sequencing of these general issues in the interview schedule. The first concept to be presented is the nurse interviewees' experience of the donation process. The philosophy of hermeneutic phenomenology requires the origins of feelings, related to the experience, to be determined to assist interpretation of meaning. Therefore, it was important to discover how, and when, nurses' feelings about the donation process develop.

## **Experiences of the donation process**

It quickly became apparent that all of the nurses, who had experienced donation, defined their experiences in terms of their perception of the lasting impact that the situation had, on them and on the deceased's relatives. However, few nurses ( $n = 4$ ) reported actual, rather than inferred, emotions expressed by the bereaved relatives. The experiences of the interviewees were grouped into two main categories according to the level of overall evaluation as perceived by the nurse. Therefore, some were classified as being 'good', whereas others were evaluated less favourably, and formed the 'bad' experience category. The interview data relating to each of these concepts will be presented now.

### **'Good experiences' of donation**

'Good experiences' were those circumstances that enabled the nurse to provide the relatives, of the dying patient, with high quality care and support. One element of the 'good experience' was the satisfaction felt when all concerned with the dying patient were seen to be adjusting to the changing personal

circumstances. This emergent theme was described as ‘coming to terms with the death’.

*‘Coming to terms with the death’*

There appeared to be several dimensions to this theme, each emerging at different times during the interview. One aspect that generally emerged early on in the interviews focused on the relatives of the dying, or deceased, patient. The nurse interviewees reported having experienced feelings of satisfaction when they believed that their actions, as well as those of other members of the health care team, appeared to have helped the family members begin to accept the death or, at least, to have realised the terminal nature of the situation. Feeling positive about the donation experience did not appear to depend on a successful retrieval or transplantation, as long as it was felt that the relatives had been able to make the decision that was right for them, at that time.

Early in the interview with Dave, an A&E staff nurse, he recalled some of the experiences of organ and tissue donation. One family appeared to be prominent in his mind. He spoke of, what he defined as, a tragic situation, in which a young man died soon after being admitted to the department following a cardiac arrest. This man’s wife could not accept the death. For several hours Dave devoted a substantial amount of time and emotion to supporting and comforting this woman and her young family, trying to help them come to terms with the death. He commented that

*“After about six hours she (the patient’s wife) began to accept the death and then she suddenly came out with the words that she wanted organs donated. By then it was too late for kidneys, so they (the transplant team) actually went for corneas on that gentleman.”*

*(Dave, A&E Staff Nurse)*

This extract fails to reveal the level of conflicting emotions that were expressed when he recalled this event. He reported that he felt pleased that she was accepting that her husband had died, but this was mixed with frustration, that this acceptance, and subsequent donation wish, came too late for kidney donation to be considered. Dave said that he could have asked about donation wishes earlier but did not because he felt that she would not have coped with a request at that time. Although the young man's kidneys would have been suitable for donation, Dave's over-riding concern appeared to be for the grieving wife. The reported satisfaction that he felt, when she raised the subject of donation, appeared to stem from the wife's apparent realisation that death had occurred. He believed that the support and care that he had given to this woman had helped her to begin to come to terms with the death. The extent of her adjustment to the changing situation was demonstrated, according to Dave, by her ability to discuss her deceased husband's wishes at a time of heightened emotions.

The feeling of well-being, or satisfaction, experienced by Dave might also have been due to relief that the deceased's wife had initiated a discussion about donation. Other nurses recalled circumstances where the potential donor's relatives had raised the subject of donation. One staff nurse, working in the A&E setting, spoke of her satisfaction that the relatives, of the deceased patient, felt able to come to talk to her about death and speak about donation. Such feelings of enhanced self-satisfaction were not restricted to circumstances where donations were possible, and which produce an obvious reward, such as the realisation that the donated parts offer opportunities for improving the recipients' quality of life. The same nurse, who told of the relief felt when relatives suggested organ or tissue donation, admitted that she had never seen the donation process culminate in organ or tissue retrieval.

The job of facilitating coping, or satisfactory adjustment to the changing circumstances, appeared to extend to the self, and to colleagues, as well as to the bereaved relatives. This emerged to produce the next theme, described as 'professional satisfaction'.

*'Professional satisfaction'*

The self-satisfaction, that followed a 'good' donation experience, came from the knowledge that, as a nurse, all had been done to ensure that the relatives' needs had been met. This was not accomplished however, without some cost to the professional. Later in his interview, Dave was speaking about the personal consequences of participating in the donation process, including being emotionally drained following such experiences. He reported that he has difficulty sleeping afterwards, because of re-running the experience in his mind. However, this did not discourage, or dissuade, him from future participation. He said that he loved the work of A&E nursing and had volunteered for a more active role in promoting donation awareness among the departmental staff, because he found dealing with relatives very satisfying:

*"It is one of the few times when the staff see things through to the end, which is very memorable. You need different skills but often you aren't dealing solely with that one situation. Very often you are going in (to the relatives' room) offering a cup of tea, having a chat then saying "right" then going off and doing another job. It can be difficult, particularly if you have had a paediatric arrest and then someone comes up and complains about the delays in the department. Or a member of staff makes a joke - you feel like blowing."*

*(Dave, A&E Staff Nurse)*

This account emphasises the different pressures on the A&E staff, including competing demands on time and emotions, when they are caring for patients in a busy emergency department. The staff reacted differently to such pressures. Some make jokes, as mentioned by Dave, and this was something that he did not like. However, during this and other interviews with A&E nurses (n = 4) in both health regions, feelings of satisfaction emerged particularly when members of the

health care team supported each other and worked hard to make the donation experience a 'good' one for all concerned.

Dave's memories and recollections reflect the predominantly positive views of all of the nurses interviewed who had first-hand experience of caring for a potential donor, when recalling aspects of each situation that were not viewed so favourably. The nurses appeared to balance any negative points that they raised, with positive ones. The provision of support, and the feelings of satisfaction when the nurses perceived that they had provided a good level of care, came across very strongly when deciding if an experience was 'good' or 'bad'. Not all of the nurses, however, found the donation experience wholly satisfactory. The same issues of time and emotional costs that, for Dave, were motivating factors, were inhibitory for others and led to them labelling some experiences as 'bad'.

### **'Bad' experiences of donation**

When the nurses were asked if they had ever experienced organ or tissue donation during their professional career, all felt compelled to recall at least one experience that they considered to have been 'bad' in some way. Even the six nurses, who had reported no direct experience of the donation process, began to speak, spontaneously, of examples of 'bad' experiences that had been told to them, a form of hearsay. The circumstances surrounding the potential donor's death, the behaviour of other health professionals, and the lack of support given to the participants of the donation process, all contributed to the experience being considered as 'bad'. The common themes that reflect these determinants are discussed now, beginning with the opposite scenario, to that described by Dave, in which there was considered to be too little, rather than sufficient, attention paid to the feelings of the bereaved relatives.



*'Insufficient attention given to the family members' feelings'.*

The recollections, of the nurse interviewees, highlight the unexpected nature of the circumstances that preceded admission to hospital and the subsequent experience of the donation process. None of the nurses spoke of any patients who were planned admissions to hospital, possibly for terminal care. Therefore, it must be assumed that all of the experiences that were discussed focused on emergency admission or on unexpected death. This is pertinent because previous research (Evans, 1995; Kiernan, 1995; Pelletier, 1992; Sque, 1996) suggests that nurses, and other health professionals, associate unexpected death with reduced coping by relatives. Nurses may avoid asking about donation wishes because of the mistaken belief that the action may cause additional distress for the relatives. The majority ( $n = 18$ ) of the nurse interviewees identified at least one occasion when the handling of the request stage of the donation process was deemed to be less than satisfactory. The concern that emanated from the nurses' perceptions of the effect that insensitive handling of the request appeared to have on the family members of the deceased is highlighted by Julia, a staff nurse who worked in an intensive care unit.

Julia spoke about her patients for whom organ donation became a possibility, following a diagnosis of brain stem death, during the eight years that she had practised in various intensive care units. Julia tended to focus on the relatives' emotional reactions to the admission to the ICU, rather than the actual nursing care that the patients received. One patient, in particular, stuck in her memory. Several years had passed since her involvement with this patient, but the clarity of her recollections implied that time had not diminished the impression created. Julia remembered that the relatives appeared to be very distressed. Their mother had collapsed in a supermarket car-park exactly a year to the day since their father had died. Julia expressed her concern about the amount of distress that the family were experiencing, commenting that she felt that it would not have been appropriate for her to remain in the room when the donation request was discussed with the relatives. She said that she thought that this would only add to their grief and distress.

It is difficult to deduce, from Julia's recollections, the precise source of her anxiety or concern regarding the discussion of donation. Julia appeared to be experiencing an element of personal distress, caused by the thought of relatives being asked to consider organ donation, in, what she perceived to be, inappropriate circumstances given the timing of the death one year after their father's death. This personal distress, however, was partially disguised by Julia's expression of concern that her presence in the room, rather than the request itself, would be the factor that increased the relatives' distress. In reality, the presence of a nurse, when a request for donation is made, has been found to be supportive, not distressing (Pelletier, 1993).

Julia made other remarks that appear to reflect her concern over the donation process, particularly the phase of donation discussion. She commented that, on another occasion, she felt that the actual discussion of donation could have been handled more satisfactorily. She believed that the staff had pressured the patient's wife into agreeing to a request for donation. The manner, in which the request was made, was not to Julia's liking, nor so, the environment in which the request was made. She said it should have been made in a quiet room, away from the busy ICU, rather than in the doctors' office. The following extract from Julia's interview illustrates these points:

*"It was done too abruptly by the male doctor. When the Transplant Co-ordinator asks, the manner is much nicer - it is done in a warm and caring manner. Sad news is broken in a good way, with an explanation of what has happened, what the prognosis was, and then the family is asked to think about donation. The family is given time and support, because it is a traumatic time and the prognosis is difficult to take in."*

*(Julia, ICU, Staff Nurse)*

Although Julia had, subsequently, experienced donation situations which, she felt, were handled far better, clearly this bad experience had adversely affected her future behaviour. She admitted that she would not suggest donation to a bereaved family, because of the manner in which some families were treated. However, later in the interview, she conceded that more recent, positive, experiences had positively changed her perception of donation and the donation process, as this extract from her interview illustrates:

*“So I’ve gone from not wanting to do it, to, well, because there is someone else who will speak to the relatives, I am more inclined to say, well, could we use this?”*

*(Julia, ICU Staff Nurse)*

Thus, Julia appears to be much more comfortable with a supportive role in the donation process, rather than one that requires her to take sole responsibility for making a request for donation. She admits that, because of her experiences, she is unlikely to be the one to ask. Donor identification and the communication of her observations concerning donor potential, appear to pose fewer problems for her.

Another nurse, Tracey, could also recall in detail, a donation request that she had been involved in. She accompanied a doctor, when he went to ask a member of a patient’s family about donation. In her opinion, the request was also made at the wrong time, with a lack of regard for the relatives’ feelings. She felt that the relative, a brother, was emotionally incapable, at that time, of comprehending the enormity of the donation request, and was not fit to make an informed choice. The following extract from her interview emphasises this point:

*“He was so distraught after just hearing the news that his brother had died, and the doctor was then asking him if he would like his brother to be a donor. That sort of questions was a bit, um, they didn’t want that. They wanted to grieve for a moment - I don’t think*

*they really wanted to hear anything like that. They needed time to take the news of his death in.”*

*(Tracey, CCU, Staff Nurse)*

The reaction of the relatives, combined with the nurse's perceptions that the timing of the request was insensitive, made the experience a bad one. Her feelings about this remained strong, even after three years. Julia's, and Tracey's, experiences provide some insight into the origins of behaviour, particularly the factors that determine or influence nursing actions. If these nurses had been asked to choose whether or not to approach these relatives and ask about donation, clearly, no request would have been made. These nurses believed that a request was inappropriate, given the relatives' apparent grief and distress. However, such emotions are a normal reaction to death. The nurses do not appear to be acknowledging this. Their own feelings appear to be clouding their professional judgement.

Other experiences were described as being 'bad' when lasting negative impressions were produced by the act of organ or tissue retrieval, rather than the request for this donation. This may also have been behind Julia's, and Tracey's, reactions to the experiences that were discussed above. The emergent theme focuses on perceptions of the way that the potential donor is to be treated during the retrieval, and is called 'when the donor is treated without respect'.

*'When the donor is treated without respect'.*

It became apparent during my discussions with Jeanette, an experienced nurse in caring for potential donors and recipients, that the behaviour of others, towards the potential donor, could influence perception of the donation experience. Jeanette felt that one experience was particularly bad, because of the impression created by those organising the donation process. Jeanette felt strongly that there

was a rush to retrieve organs and this generated an impression of ‘grabbing’ the organs, which was not, she felt, in keeping with a caring profession. She said:

*“When you lose sight of the fact that it is a human being, a warm, living human being, at that time, and it all becomes centred on taking the organs from that person, then it would be a bad experience. Yet when the whole thing is treated with compassion, from a personal, patient point of view, then you feel better inside about it. That person isn’t just a vessel for the organs - they are someone’s relative.”*

*(Jeanette, ICU, Staff Nurse)*

Jeanette focuses on a situation when, she felt, the medical staff proceeded too quickly, before the family had actually been asked for their views on donation and had not given permission. This disturbed her because such actions conveyed the wrong impression to relatives and to other colleagues. Her personal reactions to this apparent disrespectful behaviour may have been heightened, however, by her subjective interpretation of events. At no time, in the interview, did Jeanette mention actual comments, made by the relatives of potential donors, to support these perceptions. They represent, therefore, Jeanette’s interpretation, reflecting her personal, rather than professional, attitudes to the care that should be given to the dead and how this fits with the donation process.

Personal factors appear, also, to be creating the next common theme, called ‘words evoking negative mental images’. This represents another concept, which resulted in the donation experience being evaluated as ‘bad’. Words, used by some health professionals, to describe the retrieval stage of the donation process were notable for the images that they created.

***'Words evoking negative mental images'.***

The terminology, used by health professionals, can be misunderstood even by those within the discipline. The donation process is no exception. Words, such as 'snatch', 'harvest', 'procurement' have migrated from the USA, where they are still used to describe the act of retrieval of organs or tissue. Unfortunately, they contrast sharply with the less emotive terms used in the UK, such as 'retrieval', and 'donation'. The American jargon appears to convey strong negative images that created lasting impressions on a few of the nurse interviewees (n = 6). Julia, whose recollections were mentioned earlier, described how her first experience of the donation process made a deep impression upon her due, in part, to the language that was used. The term 'snatch' really stuck in her mind. She said that the behaviour of the health professionals conveyed the impression of people who wanted to 'grab' or 'steal' the parts that were no longer needed. She felt that the whole process was made to feel illegal or underhand, and she did not want to be associated with such activity.

The above themes highlight the effect that previous experience can have on future behaviour. However, not all 'bad' experiences result in lasting negative behaviour. Sometimes, such experiences can act as motivating factors to promote actions that ensure that the issues, that made that experience 'bad', do not occur again. Therefore, the characteristics of the individual nurse also appear to determine the eventual influence of donation experience on future actions, which can be described within the theme 'nurses' subjectivity and the donation experience'.

***'Nurses' subjectivity and donation experience'***

The donation experiences of these nurses have, as a common feature, the subjectivity of the nurse. The reasons given by the nurses to explain why some experiences could be called 'good', whilst others become labelled as 'bad',

reflect the subjectivity of the criteria with which these nurses define care as being high standard, or sub-standard. However, associated, somewhat inextricably, with this reasoning is the individual make-up of the nurse. The interpretation of donation events appear to reflect the nurses' personal attributes, and provide insight to the factors that cause concern within nursing. Nurses from both regions identified the themes related to experience, reflecting, perhaps, issues that might be apparent in the wider population.

The recollections of Sheila, a ward sister with many years of experience on which to draw, highlighted how individual nurses react differently to similar events. Sheila, too, could recall all the patients who had been diagnosed as being brain stem dead, who she had cared for over her nursing career. She became very emotional at times as she reflected on these experiences. Sheila readily admitted that not all were 'good' memories. To her, experiences that were 'bad' meant that the family of the potential donor had received care that, in her opinion, was substandard: kept waiting without adequate explanations and with inadequate communication between the family and the health professionals, not unlike the explanation given by Julia.

However, unlike Julia, Sheila's experience of the donation process proved to be a vital component for improving the care that she delivered in the future. Julia's experience reinforced her view that she should not participate in donation request. Sheila's, however, caused her to reflect on her practice and make modifications that would enable her to provide a better service to those in her care. She recalled her involvement in one case in which the reason why a mother decided to donate her son's organs became clear. Organ donation enabled the donor's mother to cope with the tragedy, through her belief that her son's death had not been a waste. She told Sheila that God had intervened and that her son now lived on. The mother, apparently, took immense pride from the fact that she was able to do what her son would have wanted, and that it was an honour to be his mum. Sheila commented that this experience removed any previous doubts about the donation process that she might have been harbouring in the past.

Sheila's recollections suggest that such experiences make it more likely that those nurses, who feel strongly that donation and transplantation can be beneficial to society, would be more willing to participate in the donation process in the future. It seems that, for some nurses, experiences that suggest that the relatives obtain some benefit from organ or tissue donation can help to diminish fears or concerns, thus the benefits of participation outweigh any perceived costs. Sheila still has doubts about her own ability to raise the subject of donation with the family members. However, she commented that her extensive contact with donor families has helped to reinforce her own beliefs about the positive aspects of donation.

Sheila was not alone in expressing doubts about aspects of the donation process. All the nurse interviewees mentioned at least one factor that generated unease, or discomfort. Previous experience of caring for potential or actual donors, and their families, appeared to help the nurses to become more aware of the needs of the family members. However, a dichotomy of emotions seems to be triggered by this experience. The belief that transplants transform life reinforces pro-donation feelings, and evoke a sense of satisfaction and well-being. However, concerns about the possible negative effects that the donation process may have, on the patient, the relatives, or on the individual nurse practitioner, produce anxiety and other inhibitory emotions. The strength of the inhibitory effect is mediated by the inherent characteristics of the nurse.

Experiences of donation could lead to the development of pro-donation feelings or, conversely, could deter the practitioner from any active involvement in the future. Words used by some members of the transplant team or by some of health professionals created vivid mental images that gave an often inaccurate, yet lasting, portrayal of the retrieval stage of the process, causing doubts to grow. The length of effect on behaviour of 'bad' experiences appeared to vary, effecting avoidance of involvement in the donation process. Other experiences, that were handled far better, served to reduce the impression created by the bad.



Behaviour, therefore, appears to be determined by factors other than experience alone. The survey data had suggested that this was the case and more details, of the influence of the other factors, emerged over the course of the interviews. The first of these to be discussed is knowledge of the donation process and the extent of its influence on nurses' participation behaviour.

## **Knowledge and understanding of the donation process**

Despite results from the inferential analyses undertaken in Study One, indicating that knowledge of the donation process had a relatively weak effect on nurses' perceptions of their ability to discuss donation issues with bereaved relatives, the written comments of respondents introduced doubts about the accuracy of the statistical findings. Knowledge related issues were cited by 34% (n = 40) of the Study One, nurses' who offered comments. Knowledge of the donation process was, therefore, included as a topic for discussion during Study Two. The source of any knowledge, as well as nurses' thoughts about the effect that improving knowledge would have, on the ability to talk about donation issues, were explored. The interview data enabled a number of conclusions to be made about the perceived knowledge levels, and importance that nurses' place on the possession of knowledge to help them with their practice. These will be discussed now, beginning with the nurses' thoughts on their knowledge of donation issues.

### **Perceived knowledge levels**

When asked to comment on their own levels of knowledge of the donation process, 40% (n = 13) of the nurse interviewees thought that their knowledge of donation issues was good or adequate. No grade, clinical area or health region predominated.

The interview data uncovered some evidence of poor knowledge, particularly concerning donation of tissue, in all of the clinical areas, confirming findings from Study One. Tissue donation evidently came as a surprise to several of the nurses (n = 4), because they commented that the thought of donation applying to their areas of work had never occurred to them. Even nurses working in intensive care units, admitted that tissue donation rarely crossed their mind. They reported that the emphasis was on organ donation instead. The words of Jeanette, an ICU sister, with extensive donation and transplantation experience, sum up the views of the majority of the interviewees:

*“Tissue donation? I really don’t know much about that side. Major organs are known about but not these newer things. Generally, we get multi-organ donors on the unit but tissue alone is rarely considered when patients die outside the criteria for organ donation. It is possibly due to a lack of information about the benefits of tissue transplantation.”*

*(Jeanette, ICU, Sister)*

Discussions with the transplant co-ordinators, in both health regions, supported Jeanette’s comments. The emphasis certainly appears to be on organ rather than tissue donation. If all patients who died in hospital were considered for donation potential, the majority would meet the criteria. However, the transplant co-ordinators would find their, already high, workload increased and, perhaps, would not be able to deal effectively with this. One has to ask if the perceived life-saving benefits of organ donation motivate the staff, including transplant co-ordinators, to consider the organ donor potential of patients, whilst tissue does not appear to evoke the same feelings. Tissue transplants, such as heart-valves and corneas, may not be seen, by health professionals and the lay population, to have such an immediate life-saving quality as heart transplants (Brady, 1990). The nurse interviewees, who had not previously considered patients as potential tissue donors, suggested that more education was needed to raise awareness among hospital staff and the public.

The importance of knowledge came across very strongly in the interviews as, time and again, the nurses spoke about the knowledge that they felt was required when caring for the needs of the potential donor's family. Appearing to be knowledgeable emerged as an essential pre-requisite for involvement in the donation process, confirming a finding from Study One related to respondents' views on the qualities of the requester. Providing a professional, high quality, service called for possession of a higher level of knowledge, when compared with the amount of knowledge needed to satisfy their own personal requirements when considering donation intention. A medical ward staff nurse, Olga, summed up her feelings when she said:

*"I wouldn't like to describe it (donation) to a bereaved relative - wouldn't feel that I knew enough to do that ...They have so many questions to ask - but then I suppose that you do get people who have already made their decision, like me."*

*(Olga, medical ward staff nurse)*

Olga's comments imply that she made her own personal decision about donation intention with minimal information. Thus the decision-making was intuitive, rather than rational. However, the decision to donate someone else's organs, or tissue, is perceived as requiring far more information. The need to allow others to have the opportunity to make an informed choice was of great importance to the nurses. There was also an acknowledgement that nurses have a part to play in the provision of information. All of the interviewees, with the exception of Sarah, the health care assistant, recognised that questions would need to be answered. They indicated that knowledge of the donation process would enhance their self-confidence, enabling them to be more responsive to the relatives' questioning, and make participation more likely. There was a shared view, however, that the provision of education, in this aspect of health care, was perceived to be lacking. It is pertinent, therefore, to turn to the source of nurses' knowledge to discover

where, and when, the subject of donation had been studied, since this information will help to determine the most appropriate method for the future.

### Sources of knowledge

Two key sources of knowledge were discovered: formal study days arranged by the transplant co-ordinators; and informal information passed on by other people. The nurse interviewees (n = 10) who were working in areas where organ donation is more common, such as ICUs and A&E departments, commented that some of their knowledge had been obtained by attending a study day or session, which they found to be useful. However, most of their information about donation came from other health professionals, particularly the medical profession, during the assessment of brain stem death. Maria, a staff nurse who had worked in the ICU setting for nearly five years, spoke of this informal gathering of information which, she felt, had helped her to make sense of a situation that can be confusing, and distressing, for the professionals who are performing the care. This is illustrated in the following extract from her interview:

*“I would say that my knowledge of donation was fair. I wouldn't say that its by any means excellent, and it's come to be fair only because the doctors do the brain stem function tests and go through the tests with you. What they are looking for and then go through the aims that you need - how to look after the patient to ensure that their organs are in the best condition.”*

*(Maria, ICU staff nurse)*

For other nurses, their knowledge originated from personal experience, or by exposure to the media. The individual efforts, made by the nurses, to enhance their knowledge became evident during the interviews. Two nurses, who

indicated that they did not really agree with organ donation, still reported that they had made some limited efforts to find out more about the donation process. The relatives of the patients had asked them questions, which initially they could not answer. The nursing press had been a source of information for these nurses. Other nurses spoke of an extensive search for information to satisfy their own personal curiosity. Kate, a staff nurse who was working in a trauma ward, said that she had managed to acquire information by visiting specialist units where donated tissue was stored. The following extract from her interview depicts this search:

*“Oh I picked it up as I went along: visiting the bone bank in Leicester; skin was mentioned during a visit to the operating theatre; and my knowledge of corneas comes from talking to other nurses who work on the ward where corneal transplants are performed.”*

*(Kate, trauma ward staff nurse)*

Kate also mentioned that promotions, held within the hospital, to support the transplant unit, helped to raise awareness of the need for transplantable organs. These received a lot of publicity by the media, who were also credited for helping to inform the nurses. She also mentioned working in a nursing home with a nurse who had been a transplant co-ordinator and so, in Kate’s own words, she “picked her brains”.

The absence of the school of nursing as a source of donation-related information was noticeable. None of the interviewees could recall the subject being discussed during their nurse training. Kate also commented that she had received no information about study days to do with donation even though the hospital regularly sent details of courses at the local school of nursing. Kate had, clearly, made efforts to improve her existing knowledge but she still did not know how to continue this through formal education. Kate appeared to be frustrated by health care educators who, she felt, should be doing more to equip nurses with the

necessary knowledge and skills. This is reflected in the theme of ‘frustration due to lack of education provision’, which will be described now

### **‘Frustration due to lack of educational provision’**

The frustration, evident in Kate’s comments, was not unique. Kate’s focused on the school of nursing as the education provider, however, for others, the focus of frustration was on the transplant co-ordinator as an education provider. Nurses (n = 7) from both health regions expressed views that the transplant co-ordinator could do more for nurses particularly those in the non-ICU areas. The nurses wanted further information and were generally unaware that patients, on their wards, had the potential to become donors. It seemed that awareness of the need for information was heightened when the issue of donation was raised by the relatives’ of the patient. The nurses reflected that they did not know how they should respond to such a request. The comments from Jenny, a staff nurse on a medical ward, highlight this point:

*“I’ve never seen the co-ordinators but then they might be under the impression that the ward is still care of the elderly.... Just recently we had a lady admitted and she had a letter on her saying that she would like her organs to be donated after her death. I remember seeing this thinking it was so unusual. I made sure that it was pointed out to other members of staff as they needed to know that it was there...I’ve never seen anything about donation, nothing gets posted up to the ward.”*

*(Jenny, medical ward staff nurse)*

Some of the apparent frustration that emerged may have been generated by the research itself. The survey (Study One) appeared to have motivated some of the interviewees to consider donation issues for the first time. Participation in the

interview generated further thoughts on the subject. Consequently, when Audrey, a surgical ward sister, commented on knowledge levels of donation, among the nursing staff on her ward, she implied that she had been prompted to discuss the subject of donation with colleagues. Audrey elaborated on ways of introducing the assessment of patients' donation intentions in her clinical area. She felt that her own lack of knowledge, and that of colleagues, would be problematic. The following extract highlights her concerns:

*“The knowledge levels I think are minimal. They are probably a bit more than in some other places in the hospital because the renal patients come to the hospital and may stay on the ward. However I have never seen the transplant co-ordinator and even though one of the consultants is the transplant surgeon, it doesn't increase the knowledge on the ward. It doesn't really impinge on ward life and so it is not of interest! ... I feel that the co-ordinators don't sell themselves enough. ... We need help with how to approach the subject and how to handle the situation.... I feel afraid that I would not be able to answer questions...”*

*(Audrey, surgical ward sister)*

Audrey's comments were not uncommon among the ward-based nurses who were interviewed (n = 15). Unless someone, or something, such as a media article, engenders an interest among ward nurses, issues such as organ donation are not considered seriously, because they do not appear to be relevant to the ward environment. The nurses' personal views, about donation intention, have little influence on behaviour in clinical areas where donation is not normally considered to be relevant. The majority of ward-based nurses (n = 12) reported that they were personally willing to donate their own organs. However, they admitted that donation was not a subject that they thought applied to their wards. The research, they felt, had compelled them to think about donation and their area of work. This created a mixture of feelings, including guilt and anxiety. Guilt because they could, possibly, have offered the opportunity to donate to

patients who had died. The anxiety originated from the thought of actually asking a patient, or the relatives, about something that only occurs after death. Such thoughts will be discussed in more detail next, together with the factors that the interviewees identified as influencing their decision making, in relation to participation in the donation process.

## **Participation in the donation process**

The nurses were given an opportunity, during the interview, to expand on their response to a question posed in Study One, asking who should make the donation request to relatives and why, considering also, their views on personally performing this role. Their responses corroborate the conclusions, made from Study One data, that there are strong feelings both for, and against, developments that might result in nurses playing a more active role in recognising and, subsequently, discussing donation. The common emergent themes, related to this section of the interview schedule, supportive of nurse participation, included 'meeting the patient's wishes'; and 'being prepared'. Those that emerged as inhibitory factors included 'nurses' reactions to relatives' responses'; 'peer pressure'; 'unknown wishes'; and 'conflict with the normal aim of hospitalisation'. Each of these themes will now be described.

### ***'Meeting the patient's wishes'***

Most (n = 28) of the interviewees commented that they would be more willing to actively participate in the discussion of donation intentions if they had information about the patient's wishes prior to any discussion with relatives. The issue of meeting wishes was highlighted during the interview with a staff nurse, Helena, who vividly recalled her first experience of donation whilst working in a coronary care unit. She spoke of a young person who was admitted after suffering severe chest pains. When this patient suffered a cardiac arrest, and died,



his age and good health triggered an association between these attributes and the potential for organ or tissue donation. The transplant co-ordinator had spoken to the nurses on the unit only a few weeks earlier. Helena remembered what she told them about the possibility of asystolic kidney donation and tissue donation when all resuscitation efforts have failed. The youth, and previous good health, of the patient suggested suitability for asystolic kidney donation and, added to which, the patient carried a donor card in his wallet. This record, of the patient's desired intentions, was the factor that persuaded the staff to contact the transplant co-ordinator. Helena, however, commented that she could understand why the association is not made with every death. She found the process, that led to the actual retrieval taking place, time consuming. It required the attention of several nurses on the unit, which meant that they were not available to care for the other patients on the CCU. Helena also mentioned that the process was far more stressful than she thought it would be, because it was the first time for all concerned, and much of the equipment that was required, had to be sought from other units.

Although this case appears to have presented logistical and emotional problems for the nursing staff on the CCU, these do not appear to have had a long-lasting deterrent effect on future actions. Helena implied that there would be a next time, commenting that the disruption and chaos would be less on the next occasion because the unit was now better prepared for the donation process. The staff had ensured that all relevant equipment was stored on the CCU.

Patients' intentions can be conveyed to staff in a number of ways, when verbal communication is not possible, including the donor card and the NHS Organ Donor Register. However, access to the register is restricted to maintain confidentiality (Warren, 1996b). There is another option: staff could ask the patient, at an appropriate time during life. The interviewees commented that the donor card is not a good way of communicating post-mortem wishes because it is rarely found when the patient is admitted to hospital. For this reason, therefore, the case for asking about donation intentions seems quite strong.

All (n = 4) of the nurses who worked in the two accident and emergency departments suggested that the donor card is particularly ineffective in that environment. They reported that patient's property is, usually, the last thing to be searched when a patient was admitted as an emergency, particularly a life threatening one. They said that if the patient's identity is unknown, it is normal practice for the patient's wallet to be examined by the police or ambulance crew, in order to find some identification. If a donor card is found, this may be commented on, by these professionals, but this was thought to be the exception rather than the norm. The association between the possible imminent death, the donor card, and the potential for donation, does not appear to be made readily.

Several interviewees (n = 16) commented that the donor card had the potential to make the request stage of the donation process slightly easier because the person making the request, would do so knowing that they were carrying out the patient's wishes. There was a unanimously held view (n = 31) that the patient's wishes should be met and that the relatives should not have the right to refuse organ donation, as can happen in the UK's system of donation. Presently, the relatives have the final say, even when a donor card is found. The presence of a donor card, however, can ease the difficult decision to be made by the relatives. Knowledge of the patient's wishes can help the relatives to decide what should be done, because they can decide to act according to any instructions (Sque, 1996).

The interview data highlighted the cautious nature of health professionals particularly when dealing with a sensitive subject such as death, or death-related wishes. It seemed that very few would be uninhibited and talk about these subjects without some encouragement. There has to be an indication that they are doing what the patient, or the relatives, wanted. This may come in the form of a donor card, or more often, it might be a passing comment made by a family member to the nurse. Whatever the format, it appears that these cues are acted on fairly readily. Julia, who worked in intensive care, spoke of this when asked if

she had ever looked for a donor card. She didn't answer the question directly, but instead, spoke of her actions when cues about donation are offered:

*Julia: "Oh yes, if I know that someone is for it (donation), then I open my mouth and just go for it. If the family make it aware to me that its what the patient would have wanted, then as soon as we know we can't go any further, then we would get alarm bells and go for it."*

*Researcher: "Who would start the alarm bells ringing?"*

*Julia: " I would say its more the nurses. Most of our patients have been admitted to the admissions ward or somewhere, and they have gone off (their condition deteriorated), and they have come to us. The stuff is checked and bagged up (talking about the patient's property), then you chat to the relatives. If they say that my dad's always believed in organ donation then you do something about it."*

*(Julia, ICU staff nurse)*

Julia's comments indicate that a number of factors have to be present before the donation process moves forward. Firstly, there must be acceptance, by the nurses, that nothing more can be done to save the patient. Secondly, positive cues must be received, from the relatives, during informal discussions between the nurse and the relatives. It appears that, only then, will further action be taken. The health professionals, therefore, are more likely to act when they feel sure that someone, the patient or the relatives, will approve of their actions.

The next common theme is linked to meeting patients' needs. Julia implied that nurses, as primary care givers, need to be knowledgeable to respond to enquiries about donation, or convey the patients' donation wishes. Preparation and prior thought about donation are prerequisites to facilitate the acquisition of relevant knowledge thereby enhancing understanding of, and organisation within, the donation process. The theme of 'being prepared' is discussed now.

*'Being prepared'*

The nurse interviewees who had actual experience of the donation process (n = 6), commented on the efforts taken to prepare themselves, and colleagues, for the anticipated emotional and physical strain evoked by donation process. The need for preparation was recognised by most of the nurses (n = 28), when they realised they could be approached about donation at any time. These feelings were expressed, very clearly, by Sheila, an ICU sister, who, without any probing, said that nurses are usually the first people to whom the relatives turn when they want to convey the patient's wishes in relation to donation. She said that, initially, she was unprepared for this request. Later, she found, when she tried to anticipate who was most likely, and least likely, to suggest donation, that her instincts were sometimes inaccurate. An extract from her interview identifies these points:

*“Nurses are often the ones spoken to by the relatives when they (the relatives) have thought about donation. Rarely do they speak to the doctors first. I am often surprised as to who will suggest it to the staff - my gut instincts often turn out to be wrong. I was gob-smacked with one person. The vibes I was getting was that he wouldn't agree to donation if asked, but then he surprised everyone when he suggested it.”*

*(Sheila, ICU sister)*

There was general agreement (n = 27) that any doubts or anxieties should be put aside when the patient's relatives raise the issue of donation. One interviewee, however, urged caution. Sarah felt strongly that the relatives might not be conveying the patient's true wishes to the staff but, instead, acting out of self-interest. There was a danger, she believed, that the relatives' desire to donate organs or tissue, for transplantation, might over-ride any concerns that the patient might have had. A case of what they don't know about, they won't grieve about.

Nevertheless, Sheila's comments highlight the need to be able to respond appropriately to an approach, by the relatives, even when this comes as a surprise. Preparation can assist this response.

One of the A&E departments had devoted a substantial amount of time and effort to prepare staff to respond effectively, and appropriately, to the donation process. Part of the preparation involved adopting a team approach for the discussion phase of the donation process, to enhance the service given to relatives. The interviewees reported that the relatives are supported by a member of staff throughout the patient's stay in the department. The members of the team also provide a support network for each other. Therefore, if one team-member feels unable to respond to questioning by relatives, or pressured in any way, other members are there to help. Annabel, a senior member of the nursing staff in this department said:

*"We work very well together as a team. There are some times when you can pre-prepare the relatives - that is very much the nurses' role. Its actually the, um, it has to be the doctors' role to actually say 'would you consider it', um the sort of like the legality point of view."*

*(Annabel, A&E, sister)*

She continued to speak about the occasion when a doctor had to ask relatives about donation for the first time and was very anxious. Annabel explained how the team-work ethos overcame traditional professional boundaries, allowing herself, a nurse, to support the doctor during the request:

*"We asked together. You could see that it supported her. So really, although initially you have this feeling of trepidation whenever you do it, when you think that these people are going to think so awfully*

*of you, but then, you don't get that. Instinct tells you when it's OK to ask and when it's not."*

*(Annabel, A&E sister)*

This extract provides some insight into other factors that encourage participation in the donation process including intuition. Annabel reflected that she draws on previous experiences to anticipate possible reactions that she might face when considering making a donation request. Others, like Sheila, highlighted the difficulties that can emerge from reliance on intuition to inform practice, as it can result in inaccurate decision-making.

Annabel's comments highlight a further by-product of preparation, and teamwork, that forms the next emergent theme, 'protection'.

### **'Protection'**

Another emergency department nurse, working in a department where donations rarely occur, stressed the need for teamwork and a supportive working environment. A perceived benefit of team-working was dissipation of responsibility. Louise commented that team-working eases the burden of responsibility off the individual, and dissipates it among the team members. She suggested that such activity protects the patient from a singularly dominant view which could, in reality, determine the outcome for another person. This brief extract from her interview illustrates this point:

*"Well I think it is a team thing. If you have been part of a team of people who have resuscitated a person then it (the decision to ask) becomes a team decision. If you left it to one person only, it could become like someone playing God and I don't think that anyone should be in that position"*

*(Louise, Sister, A&E)*

These comments, by Louise, reflect a need for protection that is two-fold. Team-working, and joint decision-making, protect the patients from the dominant view of one person whilst also providing some security for the nurses, and other team members. Team-working may protect against unknown reactions of colleagues that could be provoked by a donation request made without team consultation. Feeling unprotected, as well as wanting to protect, emerged, also, during the discussion of reasons for nurses' unwillingness, or reluctance to actively participate in the donation process. Where protection is unavailable, for whatever reasons, a sense of hesitancy was noted. These will now be discussed further.

### **Factors discouraging nurse participation in the donation process.**

The one issue that was raised most often, and spontaneously, by the interviewees was their fear at the unpredictability of the reactions to a donation request. This appeared to heighten anxiety levels, thereby, discouraging active participation, particularly in the donation discussion stage of the donation process. The interviewees' fears of anticipated reactions of the relatives to a donation request, and of colleagues to the subject of donation being raised at all, engendered caution. That caution, in turn, emerged from the need for protection. In the absence of any counteracting factor, this fear was highly influential at affecting behaviour. Focusing firstly on nurses' fear of anticipated reactions by relatives to donation discussion, the meaning of this, for the nurses, will be discussed next.

**'Nurses' fears of anticipated reactions of the relatives' to donation discussion.'**

Despite all that has been written and widely disseminated about reactions to bereavement, including Parkes' (1986) widely cited work about the grieving process, there remains, among the nurse interviewees, feelings of inadequacy concerning their individual ability to cope with the emotions stimulated by bereavement. Closely linked to this are the fears arising from contemplation of a donation request. The nurses were unsure how the relatives were going to react, and unsure how they, themselves, would react. Thus the fear is twofold further compounding the anticipatory anxiety.

Paula, a staff nurse, responding to an inquiry about her fears surrounding talking to the potential donor's family about donation, spoke of the pressure emanating from this uncertainty:

*"The whole thing is upsetting for the family, and if they broke down on you, then you would feel really guilty - not only are you saying that they (the patient) are dying or dead but then, you aren't giving them much time to get used to the idea before the issue of donation is raised. I feel it is a lot to handle at one time."*

*(Paula, ICU staff nurse)*

Paula's comments identify shortcomings in her knowledge of the grieving process and of the normal reactions following bad news or bereavement. It should not be professionally unmanageable for the family to cry, shout, or express their feelings in some other way, following bad news. Paula worked in an ICU, where death is not an uncommon event. The high nurse to patient ratio usually results in the nurse developing a close rapport with the family members. It is quite normal for the nurse caring for patient to break bad news to the family. Yet, Paula clearly doubts her own abilities to deal with relatives who appear to



be acting normally. She appears to be imposing her own views upon the situation. It is, perhaps, her own emotions that she really cannot cope with but is afraid to admit this. Her comment, about pressure, implies that this may indeed be the case.

Maria, another ICU nurse, also expressed concern over the feelings of the relatives. She commented that a donation request might generate doubts about the underlying motives especially if the relatives had not begun to accept the death. It was important to her that the relatives should be certain that everything possible had been done to save the patient's life, thus easing the risks of the family thinking that life saving measures were withdrawn too early. Maria was concerned that such feelings might cause the family to feel guilty.

These points suggest that image concerns may underlie the fears of anticipated reactions of the family to a request. Maria stressed the need to be considered as a caring, humane, professional and was concerned that, by making a request for donation, the relatives would no longer see her in this light:

*“At the moment I feel that discussing donation would affect how the family see me - I haven't had any actual experience of discussion but if I had then I would be careful to, um, who they could see... um, it could affect the way that they see us. It could put them off, think that we are killing them off so that we can use the organs. It may let them think that we aren't doing everything that we can because um we need to..(pause). It is important to emphasise that everything that could possibly have been done, has been done, and consider talking about it with them.”*

*(Maria, Staff Nurse, ICU)*

Maria was having great difficulty even mentioning the discussion of donation as she considered her feelings provoked by the thought of making a donation

request. She was obviously concerned that a request would have lasting effects upon the way the family viewed her as a nurse. These concerns should not be interpreted as selfish. Her concern was for the long term well-being of the relatives. She wanted to ensure that they avoid suffering any guilt from their decision, and wanted to help them recover from their loss. Several of the nurses (n = 13) had difficulty expressing how they felt about this issue and here, perhaps, my professional background may have hindered rather than helped the research process. These nurses kept saying to me “Well you know, you know what I mean. You’re a nurse so you know what I mean.” I felt that, had I pursued this inquiry, their confidence in me, and the degree of security that they felt in my company, could have suffered and so I chose, reluctantly, to stop probing into this aspect of their experiences.

Nurses’ fears about the anticipated reactions of relatives to donation discussion are based on concern for others well-being. However, the literature suggests this fear to be misplaced. The deep-seated and widely held nature of this fear is evident in the comments made by interviewees. This theme of fear is maintained in the next concept to be explored. Peer pressure, and fear of anticipated reactions of colleagues appear to affect nurses’ participatory behaviour.

### **‘Nurses’ fears of anticipated reactions of colleagues to the donation process’**

Although nurses work within a team to provide patient care, they continue to be individuals. As such, they have their own thoughts and views on nursing, life and death. Incorporated, however, within the team, are also non-nursing members, such as medical staff. They too have their unique view on the world. When nurses act, they cannot be 100% certain that others in the team will respond in a like minded way. There is evidence, of this uncertainty, within the comments of some of the nurse interviewees. The attitudes and behaviour of colleagues were cited, by a few nurses (n = 6), as factors that can deter involvement in the

donation process. A staff nurse, Caroline, who worked on a medical ward, recalled her feelings on the few occasions when she had considered the possibility of donation following the death, or poor prognosis, of some of the patients that she had cared for. She spoke of the fear that she felt when anticipating the response of her colleagues, nursing and medical, if she followed her instincts and raised the possibility of donation with them. The risk versus benefit dilemma is evident here, in this extract from Caroline's interview:

*“There are a few time when you think it, you know, you think it to yourself but, um, there's two reasons why you daren't say anything. Firstly, you don't know whether or not the conditions, or the reasons why the patient has been dying, have affected them systemically. And you don't want to look a complete jerk by asking, because if the conditions meant that they couldn't be a donor then you would look like you're stupid..*

*(Caroline, medical ward staff nurse)*

Caroline evidently felt others would belittle her and challenge her judgement if she voiced her thoughts about the patient's suitability as a potential donor. She was also concerned about behaving unprofessionally. Nurses are, according to the UKCC Code of Conduct (1992a) accountable for their actions, but this still appeared to worry her, which is evident in this excerpt from her interview:

*“I think that the danger is, if I made a boob and something happened and the patient's relatives were upset by something that I said... then I would be worried that I wouldn't have the backup from the staff and that they would see me as being unprofessional, having misjudged the situation or whatever. ... Its that risk taking isn't it then and that could be a barrier. We all make mistakes.... If that happened and if*

*you didn't get the backup from your staff then that might be quite traumatic."*

*(Caroline, medical ward staff nurse)*

Time and again, during the interview, Caroline spoke of her disquiet that she would be seen to be acting as an individual, rather than as a team member. Her colleagues' reactions acted as a barrier to any subsequent involvement with the donation process. She felt that she was in no position to be seen to be rocking the boat.

It is not known how the staff would actually have reacted if Caroline had followed her instincts and suggested donation as being a possibility for her patient. However, considering that time had done little to diminish Caroline's fears of anticipated adverse reactions, this implies that the culture within the ward inhibited such freedom of thought.

As well as the interviewees' fears of families', and colleagues', possible reactions to the discussion of donation, there also appears to be fears arising from the discussion of death which will be presented now.

### **'Fear of discussing death'**

During discussions related to the meeting of patients' post-mortem wishes, the difficulties associated with the donor card, as a means of conveying this information, were identified. At present, the most accurate and, potentially, most effective way of finding out a person's post-mortem intentions is to ask them, during life. The literature identifies evidence of other inaccuracies that emanate from judgements made in relation to another person (see O'Boyle, 1998). Similar inaccuracies may occur when relatives, or nurses, make decisions on another person's behalf. It appears, therefore, more appropriate to ask the patient, directly,

about post-mortem intentions, instead of relying on the relatives to decide on the patient's behalf. However, uncovering the patient's wishes appears to present problems for some nurses.

Maria found talking about post death wishes difficult, and it required gentle probing to identify the reasons why such topics, including talking about death itself, made her feel so uncomfortable. It emerged that this discomfort derived from fears about the consequences of her actions, rather than from personal anxiety about death itself. However, her recollections suggested that reluctance to recognise that death could occur, as a consequence of the condition for which admission to hospital was required, might be a contributory factor. This is demonstrated in the comments made by another staff nurse, Angela, as she recalled hearsay about the experiences of other nurses and the responses of the patients when asked about post-mortem intentions:

*“In some hospitals I have known patients who have been asked about it (donation) and then nurses have gone through almost abuse. The last thing patients want to talk about when they have come into hospital to get better is death.”*

*(Angela, Staff Nurse, CCU)*

She went on to talk about how she would feel if a nurse asked her about dying and donation intentions when she was admitted to hospital. She concluded that she would only want to hear assurances that she would be cured, or feel better. She did not want to have to face up to the fact that death could occur at any time. Here is a further extract from her interview:

*“ I just think that if I was in hospital and a complete stranger came to me and asked me if I had thought about dying - or what do you feel about death - do you want us to take your organs? (pause) .. I know that you can say it much more sensitively but I would probably say*

*that um..(pause). If I was feeling so ill then I wouldn't want to discuss that. I would want to hear about what they were going to do to make me better."*

*(Angela, Staff Nurse, CCU)*

It is evident that Angela is subjectively, rather than objectively, appraising the situation. However, the influence of subjectivity was not confined to Angela's behaviour. Reluctance to talk openly about death-related matters with colleagues, or with patients, was noticeable. Most of the interviewees (n = 24) mentioned that part of their nursing documentation directs the nurse to inquire about patients' needs, concerns or wishes, surrounding death. However they indicated that it is rarely used. One nurse told me that her hospital, in Leicestershire, had recently excluded this from the assessment documentation for this reason.

Audrey, a surgical ward sister, said:

*"It is the one question that nurses always avoided. You can look at them (the assessment sheets) and when it was on, it was never filled in. Therefore it was removed."*

*(Audrey, Sister, Surgery)*

The reason for this avoidance does not appear to have been explored by the hospital management. Audrey volunteered that, on her ward, assessment of death-related needs was only completed when it was obvious to the admitting nurse that the patient was terminally ill, or when the patient expressed concerns about dying, such as during an anaesthetic. Her comments were supported by Sally's, a medical ward staff nurse, when she admitted that she rarely talks about death with her patients. She repeated, several times, that she does not talk about death on admission because the subject does not come into her mind. She appears to be able to block the concept out of her mind and ignore it in the documentation. She qualifies this avoidance of death issues by suggesting that she is only doing it to ease the patient's anxiety. But then she admits, albeit

hesitantly, that she does not discuss it because it is a difficult subject for her. Here is a short extract of her conversation:

*“But I think that the patients don’t raise it either. I have never even thought about it . We never discuss it. It’s not easy to admit someone and ask about death.”*

*(Sally, Staff Nurse, medical ward)*

The conversations with these nurses emphasised the extent of the inhibitory effect that fear of anticipated reactions can have on death discussion. They expressed concern that, unless phrased very sensitively, an inquiry about post mortem intentions could increase the anxiety levels of the patient and their relatives. Over half of the nurse interviewees (n = 16) expressed concern at the thought of having to ask patients, on admission to hospital, about their post mortem intentions. The timing and perceived appropriateness of such an inquiry was questioned, particularly by the nurses working in the critical care areas. Julie, a staff nurses working in CCU, was concerned that the inquiry would increase patients’ anxiety, and be detrimental to their well-being. She believed that the aim of nursing was to ease, not cause, distress. The following comments convey her concern:

*“There would be definite problems in CCU. Somebody coming in with a heart attack who is then asked if they carry a donor card would think ‘shit I am dying!’ The MI is frightening in itself and so asking these patients, on admission, would only add to their anxiety. It would give the wrong impression.”*

*(Julie, Staff Nurse, CCU)*

These comments highlight a dilemma that must be addressed before nurses are required to make such an inquiry. On one hand, there is a feeling of acceptance that someone has to identify patients’ post mortem intentions if donation rates

are to increase, and patient's wishes are to be met. Conversely, there are genuine concerns being expressed about the potential trauma that could be experienced if the subjects of death, and donation, are discussed inappropriately. Julie was speaking about the trauma for the patient, but it was obvious, from other comments made during her interview, that she was also worried about her own reactions.

To date, one investigation into this phenomenon has been located (Justin and Johnson, 1989). This was undertaken in the USA, and found that few patients objected to being asked about donation intentions on admission to hospital. Instead, it was the nurses who appeared to have difficulty dealing with their own feelings arising from such a request, a finding that can be corroborated by the comments made by nurse interviewees in the present study. One has to question the justification for the nurses' concern. Just as it is normal for relatives to express anger, distress, or other emotions in response to hearing bad news, surely it is quite normal for patients, admitted to hospital, to express emotionally, any anxiety about their future state of health.

Sally and Audrey appear to be discouraging the discussion of these feelings, by their avoidance of subjects, such as death, that might provoke an emotional response. This behaviour was not uncommon. Almost all of the interviewees spoke of instances when they had actively avoided sensitive issues because of the anticipated reactions. Often the same phrase was used to explain this behaviour; they did not want to 'open up a can of worms'.

Despite the apparent reluctance of the nurses to discuss donation intentions with relatives, or patients, they admitted that they routinely inquire about religious affiliation and next-of-kin. When asked why they did this, the unequivocal response was that details of this kind are required in case the patient's condition deteriorated. With further probing, the association was made that the information assists the nurses to act in accordance with the patient's wishes should death occur. It seems that covert inquiry about death-related information is permissible



because it rarely provokes an emotional response by the patient. Consequently, nurses have no reason to fear the asking of such questions. No such reassurance, though, can be given for the discussion of donation intentions. Lack of previous experience, fears of anticipated reactions, compounded by hearsay from other experiences, heighten nurses' anxiety. Their feelings, and fears, appear to determine any future behaviour.

It follows, therefore, that the final theme, in this section, should focus on participation, or rather non-participation, in the donation process and reflect nurses' fears about their own reactions to the discussion of donation issues. The concept of protection emerges again, but this time the emphasis is on the self. Through the chosen course of action, the nurse not only protects the client but also protects herself, or himself, from the reactions that death discussion might provoke.

#### **'Nurses' fears of their own reactions to death-discussion.'**

Julie, a staff nurse working in CCU, spoke of the specific circumstances of death that she found difficult, which included sudden death. When death was expected, she spent time with the relatives, preparing them emotionally to help them cope with the impending loss. However, when death happened unexpectedly, it came as a shock to herself, as well as the relatives. This appeared to put pressure on their relationship, particularly when the time to develop such bonds was short. Julie appeared to find the threat of more pressure upsetting. She later spoke of her fear that she not being able to answer the relatives' questions because, due to her inexperience, she was, herself, unsure of events, and did not want to confuse them further.

Claire, a junior sister on a medical ward, was very forthcoming with her views about why she would be reluctant to talk about death and donation issues with some of her patients and their relatives. She mentioned that death is still a taboo

subject and suggested that this taboo applied equally to colleagues as well as patients. She gave as an example, the way that death is still hidden away in the ward. She described how dying patients are nursed in side-rooms, away from the main ward patients. She implied that this was not done solely out of compassion for the patient and their relatives. It also reduced the contact that the nurses have with the dying.

Nurses know that death can occur at any time. However, traditional societal views of death, and the inevitable avoidance of any discussion, still appear to predominate. These nurses appear to have formulated effective coping strategies to reduce any anxiety that may have emerged when they first asked for potentially sensitive death-related details, such as the name of the next of kin and religious affiliation. These requests get couched in words that detract attention away from the true reason for acquiring such information. Thus, phrases such as 'it's routine', 'oh just something else to ask' or 'oh it's so that you don't get bothered by the vicar when he comes around', protect the patient from the reality of death, whilst at the same time, protecting the nurse from any awkward questions that they might have difficulty answering. In view of the efforts made to hide death away, it is highly likely that self-protection may be the real reason for not wanting to ask about donation intentions. Very few of the nurses interviewed in this phase of the research indicated that they had actually asked about donation intentions (n = 6). Therefore, for the remainder, it is likely that help is needed if similar coping strategies, to those that enable them to ask for other death-related information, are to be developed.

Decisions taken by nurses, in relation to death and donation, appear to be decided more by subjective, rather than objective determinants. The efficacy of this approach, when practising as a professional must be questioned. Preparation and support for the nurses must be provided if the fears, such as these expressed by the nurse interviewees, are to be minimised. The above accounts of nurses' views, experiences and feelings, project the overwhelming support, from respondents, for limited participation in the donation process. However, there

was not a clear affirmation for active participation in the donation request stage of the donation process. It is important, therefore, to clarify the roles that the nurses did identify as being ones that they felt they might be able to undertake. Such roles are discussed in the next section.

## **Becoming involved: what the nurses felt able to do**

Some of the concerns about increasing involvement in the donation process appear to stem from the traditional role demarcation that has, in the past, determined medical and nursing professional boundaries (See Mackay, 1993). Role demarcation appears to be hindering nurses' involvement in the identification of donor potential and asking about patients' donation wishes. However, a number of potential roles were identified by the interviewees, which, given the diversity of the backgrounds of the sample, increase the possibility of favourable reactions when the findings are disseminated to a wider audience. Roles include providing support for relatives in their care, and for colleagues; a preparer or proposer, one who sows the seed, and brings forward the possibility of a patient being a potential donor; and a facilitator, involved with the education of health professionals and members of the public, helping to raise awareness of organ and tissue donation. Each of these will now be discussed, beginning with the supportive role for nurses.

### **'The nurse as a supporter of relatives and colleagues.'**

Nurses have, for many decades, been reported to be providing a supportive role for patients, relatives, and for colleagues, be they nursing or medical (Glaser & Strauss, 1962; Mackay, 1993; Allen, 1997). Despite subtle changes that have impinged on UK nursing over the last decade, such as the introduction of Scope of Professional Practice (UKCC, 1992b) and the changes to doctors hours, traditional role demarcation, with the nurse providing support for medical

colleagues, continued to emerge in the interview data. Acceptance of a supportive role for the nurse was noticeable (n = 26), however, there appeared to be two facets to this role. The first was supporting colleagues who take on the role of requester. The second is being there to offer support for the relatives, during the request phase of the donation process. The interviewees' comments in relation to the first of these roles will be discussed now.

### *'Supporting colleagues.'*

The nurse interviewees (n = 26) implied that providing support and engendering a supportive ethos in the workplace were actions that could, and should, be instigated by nurses. They proposed that the outcome of such concerted action would be a culture where professionals of all disciplines could propose ideas and feel secure that such suggestions would be greeted without derision or other adverse reactions. Caroline, a medical ward staff nurse, recalled the inhibitory effect that an unsupportive work culture imposed on her behaviour. The extent of this was so great that, on several situations, she didn't say anything about donation for fear of other colleagues' reactions.

The experiences of the nurses interviewed in Study Two confirmed the findings from Study One, that it was more common for nurses to be willing to act in a supportive capacity, rather than take on the more demanding role of donation discussion. At least four nurses indicated that, for legal reasons, they felt that the doctor, rather than the nurse, should be the person who informs the relatives that the patient had died, and then provide details of the events that led to this terminal state. Issues such as medical responsibility for admission, and accountability for treatment, were cited to justify such role demarcation. However, as Annabel suggested, within any team, the members will have different attributes that should be used appropriately to maximise their effect.

Adherence to traditional roles may not be advantageous. The interviewees perceived doctors as having less well developed interpersonal skills than nurses, and for this reason, the a large minority of the interviewees (n = 12) thought that it was important that nurses should be included in the team involved with requesting organ or tissue donation. There was a high degree of consensus among the nurse interviewees that nursing skills were being optimised.

Comments such as, that they were left to 'pick up the pieces' and 'deal with the aftermath', highlight the feeling of bitterness that came across during the interviews. This bitterness appears to stem from the frustrating consequences of the traditional doctor/nurse differentiation. There was an overwhelming feeling expressed by nurses (n = 20) of being seen as a lesser person, of less value to patient care than the doctor. The nurses appeared to be willing to participate more actively but wanted some positive assurances that their role, or input, would be valued by all colleagues, medical and nursing alike.

#### *'Overcoming traditional role differentiation'*

Despite the professional requirement for advocacy and accountability, this study reveals nurses' fear of repercussions, arising from venturing beyond any traditionally established boundaries, and the ensuing reluctance to be the ones to initiate a discussion about donation.

The nurses, working in departments such as intensive care and accident and emergency, that had protocols to help guide decision making in relation to organ or tissue donation, indicated that roles are determined more by tradition than by ability. The doctor was the person who traditionally told relatives the diagnosis of death. This would be followed, at some appropriate time, by either the nurse or the doctor or both, raising the subject of donation. Despite this observation, the nurses indicated that they believed performance should be based on ability rather than designation.

A paradox was emerging without, it seems, the nurses being aware of its existence. Few of the nurses indicated that they felt confident to undertake additional roles or become more involved in the donation process. The majority of nurses (n = 30) did expressed a willingness, however, to increase their involvement once further training had been given. It was interesting to note such a demand for training because the nurses also told of their observations of doctor-relative communications. The medical staff's interpersonal skills were perceived as being poorly developed and affecting the outcome of sensitive interactions. However, the comments implied that medical staff should undertake the difficult task of donation discussion, because of who they are, whereas nurses will not, until they have further training. Image issues appear yet again.

Another outcome of the apparent medical domination of the donation discussion role, might be more positive. A key motivator, to increased involvement in the donation process, might be the desire to improve on current actions taken by medical colleagues, and to offer a high quality service for the patients and their relatives. The willingness of these nurses to provide support, not just for colleagues, but also for the relatives during this time of crisis in their lives, was clearly evident in their dialogue. This role will be discussed now.

### *'Supporting Relatives'*

The type of support that the nurse interviewees thought nurses could offer relatives differed from that proposed for colleagues. Establishing good rapport and a trusting relationship, between the nurse and the relatives, were identified as key components of this role. Creating an environment in which the relatives feel secure, where time pressures do not intrude, and where relatives feel that they can talk freely without criticism, was of great importance to most of the nurses (n = 24). This may be easier to develop in some areas, such as ICU setting. The high nurse to patient ratio facilitates this. There is usually accommodation

available where interruptions are minimal, enabling the nurse and the relatives to converse in some degree of privacy. The organisation and design of general wards sometimes makes such an ideal environment less easy to achieve. However, ward nurses (n = 14), as well as those from the ICUs and A&Es (n = 10), identified this as being feasible.

Post bereavement care was also proposed as being an opportunity for extending this support for relatives. Whatever decision the relatives made, with regard to the organ donation request, appropriate care and support for relatives should be provided. At present, relatives who decide, for whatever reason, that they do not want to agree to donation, receive little or no contact with the hospital after the death. Informal discussions with transplant co-ordinators and support organisations, such as the British Organ Donor Society, identified this as being a major area of concern. Sque (1996) also highlighted inconsistencies in support provision as being a cause for concern. Six of the nurse interviewees identified such provision as a role for nurses but recognised the potential problems that they might face such as competing time demands and funding for this support.

Time was another key element in determining the extent and feasibility of this support role. It was acknowledged, by the nurses, that providing support to relatives was going to incur time-costs. One ward manager, Peter, expressed his concern over these resource implications. The workload and priorities of care on the ward might be such that it is not possible to release someone to provide, what he saw, as an extra service. He suggested, however, that a solution would be to appoint a person, preferably a nurse, to come to the ward, and provide support and information, rather than using one of the ward nurses. Peter also indicated that not all nurses have the necessary skills to establish relationships with relatives. He expanded on this point by explaining his observations of some nurses, and the avoidance behaviour that they sometimes employ:

*“Some are noticeably frightened of dealing with the family of the terminally ill. They back off, back away.”*

*(Peter, Charge Nurse, Medical Ward)*

Peter’s comments were the exception, rather than the norm. However, the resource implications, training needs and time costs were valid issues, and, given the financial constraints that face care providers in the NHS today, cannot be ignored. For any initiative to work, it must be realistic. Compromise may be required. There was overwhelming agreement that the nurse does have a role in supporting the relatives of actual and potential donors. However, it is not fair to the relatives, or to the nurses, if expectations of the services to be provided are not realistic. A service that is available whenever it is needed is more useful than one that is diverse, but time-consuming, and, consequently, achievable only occasionally.

A further role, that emerged following discussions relating to the provision of support, to colleagues and relatives alike, involved preparing others for the potential of donation. Like the supporter role, there were two facets identified, preparing the relatives for the news of death and the possible donation request, and bringing the potential for donation to the attention of others. These two aspects of the same role will now be discussed, beginning with the focus on the relatives.

### **‘Paving the way: preparing relatives for the possibility of donation’**

The interviewees suggested that the nurse could, gradually, prepare the relatives for bad news by introducing the topic of donation without exposing them immediately to the reality of death. The nurses expressed a fear that a request for donation made without any preparation, or warning, would come as a shock.



However, the action of subtly introducing the prospect of death and donation was considered feasible (n = 5).

Angela, a nurse working in Coronary Care, spoke of the shock experienced by the relatives. She described how skills, developed for managing resuscitation decisions, usually made by medical staff, that might come as an unpleasant surprise to relatives, can be applied to the donation process. Here is an extract of her comments:

*“It’s like, when the doctors come and talk to relatives and say ‘we aren’t going to resuscitate’, it’s like they (the relatives) haven’t been prepared before then. Well, it comes as a shock. Sort of, um, you try to emphasise that they (the patient) are on all the maximum therapy and they are not responding and um, you sort of pave the way really. You could do that with transplantation (meaning donation) as well. Even someone who is pro-transplantation, in that situation, it comes as a shock and could say ‘no’, yet if you had time to prepare them....(pause)...”*

*(Angela, Staff Nurse, CCU)*

Angela infers, by her comments, that the preparatory role of the nurse may help to increase the positive responses to requests about donation. By facilitating early consideration of the likelihood of death, the relatives are being given time to comprehend this information before a donation request is made. Angela had never thought about the possibility of her patients being donors, before the interview, and therefore, the slightly hesitant manner of her speech reflected the pattern of thinking that was taking place as she considered these issues. Her thoughts, however, emphasise the level of her interest in developing a role for nurses in the donation process, in the CCU.

In another interview, Annabel discussed her feelings when she participated in a donation request for the first time. Annabel was very forthcoming with her recollections and views and required only minimal prompting. She gave very similar reasons as Angela to justify her involvement. She emphasised the contact with relatives prior to the request, and the opportunities that this presented in relation to preparing them for any news. The time during which trust and a professional relationship could be developed, enabled the nurse to weigh up the situation, and reach a decision about the appropriateness of any subsequent donation request. Annabel was a fervent believer in using intuition to guide her practice when no other information was available.

A different perspective was given by Juliette who worked on a medical ward where deaths are common but, despite this, donation is rarely considered. She, personally, had not thought about the issue of donation as being relevant to her patients on the ward. However, once the possibility dawned on her, she spoke of the type of involvement that she thought general ward nurses should have in relation to the donation process. She described some of the difficult tasks that nurses on her ward currently perform, such as telling relatives of the death of a patient. She believed that nurses wouldn't have, in her words, 'a great problem in asking'. When asked to qualify this, she explained that the type of nursing carried out on her ward enabled the nurse to care for the patient and the family in a holistic way. Visiting times were, generally, not restricted, permitting more contact with the families of the patients. She said that, personally, she could not think of any circumstances that would make her think twice about asking about donation intentions. She felt well placed to tease out the relatives' feeling about donation because she could usually establish a close relationship with them early in the patient's stay in hospital. Juliette believed, strongly, that this was a normal part of the caring relationship between the nurse and the patient's relatives. The same relationship, she believed, would enable her to begin to set the scene for any future request thus allowing the topic of donation to be introduced gradually.

There were no clinical areas where this preparer role was thought to be inappropriate. Additionally, there was a general feeling of acceptance that nurses had certain skills, developed over time, through experience of death-telling and involvement in other sensitive informing actions, that could, and should, be applied to the donation process. All the qualified nurses (n = 30) mentioned trust in the professional relationship between the patient's relatives and the nurse caring for the patient. This emerges as an important precondition, easing the difficult task of donation request for the nurses. This was clarified by the experiences of the nurses, in A&E departments, who had little time to develop and establish the bond of trust. They had to work very quickly to form a relationship with the relatives. Asking about donation, in this environment, appeared to be more daunting but still one that the nurses were willing to be involved in.

Despite the apparent reluctance of nurses, to undertake a primary role in donation discussions, it became apparent that some of the nurse interviewees had undertaken this difficult task, and would do so again. In general, however, more covert activity appeared to be preferable. Such behaviour was evident in the comments made in relation to preparing the way for donation discussions with the relatives. As Allen (1997) identifies, nurses continue to direct care decision-making through covert, but not necessarily subtle means. This behaviour, in relation to the second facet of the preparer role, involves colleagues, and will be discussed now.

### **'Covert activity: planting ideas in colleagues' minds.'**

The close professional relationship that can form between the nurse and the patient, or the patient's relatives, creates opportunities to elicit and communicate, sometimes sensitive, information, such as patients' post-mortem intentions. Patients and relatives often feel more comfortable speaking about such issue with nursing staff, than with medical staff, whom they may have met only

infrequently. Benner's (1984) work, 'From novice to expert', contains excellent examples of this. The nurse becomes an advocate for the patient to ensure that, wherever possible, the patient's wishes or views are conveyed. There is evidence of such activity in this investigation.

Nurses, from both health regions, indicated that they had a role to play in conveying patients' wishes, when known, to other health professionals. Most of the nurses, (n = 24), expressed this directly, clearly identifying the nurse to be best placed to raise the issue of donation with medical colleagues. For example, Julia, working in CCU, emphasised a tripartite role for nurses. Raising the subject of donation with the doctor; whilst providing support for the family members; and acting as a liaison person, enlisting the help of other professionals. She believed that, by doing this, nurses' skills are optimised, demonstrating also, the use of team-work to manage the donation process.

At least three other nurses commented that the medical staff might not think about donation, for whatever reason. The interviewees proposed that the medical staff might be exhibiting avoidance behaviour, thus introducing the possibility that medical staff experience similar fears and concerns as those identified by nurses in this research. Another proposition concerned prioritising of work. The demand on medical staff may be such that they have to prioritise. Therefore, issues that are perceived as creating more work, such as the donation process, are may be awarded a low priority, or be avoided. Julia, a staff nurse working in ICU, had her own theories about the origins of behaviour, and believed that people, in general, require active encouragement, or as she put it 'need pushing into doing something', before actions, that may require more effort, physical or cognitive, are undertaken.

Jeanette, another ICU nurse, presented a slightly different explanation for why medical staff might not think about donation, and why nurses are, in her opinion, in a good position to initiate action. She described the activity in the ICU when a patient was admitted suffering from major head injuries. The initial priority of

care focused on treatment, and recovery. All the members of the health care team worked closely to try to achieve that aim. For the medical staff, Jeanette suggested that this aim continued to direct their thoughts and actions, even when nursing staff had begun to realise that these actions were not being successful. Therefore, nurses were inclined to see beyond the physical signs and symptoms associated with a head injury, because the boundaries of their role are broader than those of medical staff. Jeanette suggested that medical staff may conclude that the patient's condition is deteriorating, but will not consider the wider implications. The nurse, possibly after talking to the family, should, according to Jeanette, be the ones who consider the possibility of donation, once all else has failed, and raise the issue with medical staff.

The ethos of team-working as a trait in ICUs, could also be considered as a rationale for Jeanette's observations. The generally supportive culture, that appears to exist in the ICU's where Jeanette and Julia work, was not evident in all of the interviewees' working environments. Caroline's experiences highlight this point. Her recollections revealed an environment that prevented her from doing as Jeanette suggested. However, evidence emerged implying that the culture is changing, from one where the nurse is a submissive hand-maiden, to one that actively engages in activities that place nurses on an equal footing with medical colleagues. Annabel demonstrates this when she commented on the support that she gave to medical staff, less experienced than herself, during donation discussions. However, this may be more evident in the specialist areas of ICU and A&E, rather than in the general wards. Six of the seven nurses, who felt unable to draw colleagues' attention to donation, were working in general wards, where traditional professional divisions may be resistant to change. Four of these nurses were based in North Wales, raising the possibility that, within this region, traditional norms remain a barrier to change.

The final role that emerged from the interview data, focused on the facilitative, or educative, responsibility that Benner (1984) assigned to nurses. This role is interrelated with that of the supporter and the preparer, by its purpose. The nurse

was identified by the interviewees, as having responsibility for raising awareness of donation, and transplantation, issues, providing information for relatives, and colleagues, and educating nursing and medical colleagues on donation-related behaviour. These will be elaborated upon here.

**'The nurse as an educator on donation-related issues.'**

Several variations on the theme of education provider emerged during the interviews, reflecting the different foci of thoughts about the beneficiaries of this role. Members of the public, patients, relatives, visitors to the clinical areas, in addition to nursing and medical colleagues were identified as possible targets for educational interventions carried out by nurses. Different forms of education or information provision were described, ranging from posters in public areas of wards or hospitals, to experiential learning.

The interrelationship between the role of the nurse as an educator, and the other proposed roles, became evident when the nurses explored possibilities for the future. All of the nurses acknowledged that the relatives, and the patients, had educational or informational needs related to the donation process that, once addressed, would facilitate informed decision-making. However, this generated anxiety. Despite an overwhelming feeling that nurses should be the ones to contribute to this support provision, it was tempered by the realisation that levels of knowledge and understanding of the donation process could be inadequate. Consequently, the interviewees considered this to be a deficit that required attention. Recognition, of this deficit, did not result in refusal to consider the prospect of active participation in the donation process in the future. Instead, it appeared to have a motivating effect, augmenting the drive to seek out information, develop learning packages, and present their newly acquired information on posters thus enabling the information to be shared with patients, visitors and colleagues alike.

One nurse did question the benefits of high visibility promotional campaigns in her area of work. Louise felt that the A&E environment was not appropriate for such displays. She qualified her comments by describing why people go to A&E departments, saying that often there is a major crisis, or a distressing emergency of some kind. She discussed the aim of care in the department, in relation to psychological support, and suggested that people preferred reassurances from the staff, not information reinforcing their fears or concerns. The following extract from her interview highlights these points:

*“People don’t want to look at these posters, they don’t want to know. They (the people) are there, they are upset, often it’s too late. When they come in here, they need to be reassured, to know that everything is all right, that they are in a safe place. Support groups, fine. Plaster it all over - where to get the information, but nothing else.”*

*(Louise, Sister, A&E)*

It becomes clear from her comments, that Louise is not against information, in fact she strongly argues that nurses do have an educative role. However, she indicated that, in the A&E setting, the most appropriate way of communicating donation -related information, was by adopting subtle approaches. High profile posters or video-based material, placed inappropriately, in for example, a room used by grieving relatives, would be inappropriate and, most likely, distressing. Whereas, inoffensive information promoting supportive information, located in a way that demonstrates sensitivity to the heightened emotions that the events leading up to donation situations, may provoke, might be received more favourably.

## Chapter summary

The phenomenological approach was adopted to elucidate the feelings that the nurses experience in relation to the donation process, and understand more fully the reasons for involvement, or non-involvement, in all, or part, of the donor recognition and donation request phases of the donation process.

There was evidence of personal and professional conflict experienced in both North Wales and Leicestershire regions. Such conflict arose primarily from the decision to meet patient's wishes and act as an advocate. This created discord with the determination to protect the patient, the relatives, colleagues and the self from any distress engendered by donation discussions, whilst wanting to address the needs of the deceased and those awaiting transplantation.

The nurses' fear of anticipated reactions of colleagues, relatives and, in some cases, the patient, were cited as reasons for not becoming involved in the discussion of donation intentions. Consequently, the concept of protection was identified as a common theme that underpinned nurses' reactions to initiating the discussion of donation. Self-protection should be considered as being a primary reason for nurses not wanting to ask about donation intentions. Image issues appeared to act as deterrents for involvement. Furthermore, for some nurses, the thought of asking relatives to consider donation, so soon after death had occurred, appeared too difficult to deal with and, thus, adopted avoidance or non-involvement behaviour instead.

The nurses identified factors that, for them, made a donation experience a good one. These included professional satisfaction, when the nurse was able to observe that the relatives were beginning to come to terms with the death, and when the process emerged as a well-organised, well-managed event. The nurses expressed pleasure when they had provided a high standard of care, throughout a period where all in the team had acted professionally and pulled together.



'Bad' experiences were also identified. Mental images induced by terminology, the disquiet experienced when the potential donor had not be treated with adequate respect, or when the relatives' feelings had not been considered fully, appear to engender feelings of dissatisfaction. This appeared to have long-lasting adverse effects on nurses' attitudes toward donation, and professional donation behaviour.

The majority of the nurse interviewees indicated that at some point, either now, or in the future, they would consider active participation in this stage of the donation process. Meeting needs was a primary motivator of future action or intentions. This variable was not measured in Study One hence, without the qualitative phase of this research, such information would not have emerged.

Another determinant focused on prior thought. Findings from Study One were inconclusive in relation to the effect of previous experience on donation discussion, and possibly misleading. The weak correlation that was found suggested that previous experience enhanced willingness to participate in this stage of the donation process. A clearer picture emerged from the interview dialogue. Through inductive enquiry, the relative importance of experience on behavioural intentions emerged, although the association with actual behaviour cannot be ascertained.

Adequacy of knowledge levels was cited as being a further factor that enhanced the likelihood of donation discussion. This corroborates the qualitative conclusions that emerged from Study One. Study Two appears to clarify sources of knowledge, and helps to formulate a clearer picture of the nurses' knowledge needs.

Traditional role demarcation and the professional divide were found to be key determinants of nurses' participation in donor identification and donation

discussion. The creation of a working environment that sustains an ethos of interprofessional support, and mutual respect, was proposed by the nurse interviewees. This would facilitate a culture in which discussions about post-mortem intentions occur freely.

The opportunity to develop leads, that emerged from Study One, and ask interviewees for clarification was invaluable for the exploration of the likely roles for nurses, in the future, in the donation process. Thus, achievable roles, to do with participation, were defined within the data. The key ones were concerned with the provision of support for relatives, and colleagues; preparing relatives psychologically and, possibly, physically for the discussion of donation; proposing donation as a possible outcome for the patient, during discussions with colleagues; and finally having a role as an educator.

The role of requester acquired little support in Study One, and this view is borne out by the findings of Study Two. Lack of confidence, concerns over poor knowledge and being unable to respond to any enquiries or questions, and concerns about the reactions of the relatives were all identified as reasons for non-involvement. There was a general feeling of willingness to begin considering ways in which patient's wishes can be identified and used to broach the subject of donation with relatives when the situation arises.

The focus of the investigation shifts, at this point in the thesis, to the future through the presentation of the results of the third phase of this research, the comparison of attitudes and knowledge of pre-registration nursing students to donation, with those of registered nurses.

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## **Chapter Seven: The Findings From Study Three: A Comparison of Student Nurses' and Registered Nurses' Views On Organ And Tissue Donation.**

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### **Chapter overview**

**T**his chapter contains the results of the comparisons made between a sample of pre-registration student nurses' attitudes and knowledge, and those of registered nurses. The findings, from Studies One and Two, inferred that any changes to the level of involvement, by nurses, in the donation process, will take time to implement. Any proposed interventions will, inevitably, affect the nurses of the future, i.e. those who are currently engaged in pre-registration nurse education. Thus, the current investigation of attitudes and knowledge to donation, and transplantation, shifts its attention to the pre-registration student sample population.

Descriptive and inferential statistical analyses were performed on the student data sets to identify similarities, and differences, between the cohorts at different stages of training. The results of these analyses will be reported, followed by those of the comparisons made between student and registered nurses.

## Introduction

The reviewed literature, related to nurses' attitudes to death, and the care of the dying, suggested that developing the skills and adopting the norms associated with the nursing profession, is a complex process. Socialisation into a profession requires the student to undergo personal development, thus adopting behaviour that is acceptable to other members of the profession (Jacox, 1978).

The findings, from Studies One and Two, enhanced comprehension of the values and norms associated with caring for the potential organ or tissue donor, and his or her relatives, as expressed by the sample of registered nurses. Several propositions became evident, that might reflect the views of the wider nursing population:

- That there is a predominantly positive attitude to organ donation and transplantation.
- That there are concerns about the current ability of nurses to raise the subject of donation with the patient's relatives.
- That given more education, and opportunities to develop appropriate interpersonal skills, nurses are willing to consider more active participation in the donation process.
- That nurses consider possession of key attributes to be the primary determinant for the requester of donation permission, rather than professional designation.
- That nurses feel confident to take on certain roles at the present time, such as supporter, protector, and educator, with a view to developing these further in the future.

These propositions are a mix of values and norms, some reflecting the views of the lay population i.e., the positive attitude to donation and transplantation (New

et al., 1994), while others appear to be nursing specific. Past experience emerged as an influential factor in the acquisition of these values and norms. However, it is necessary to explore the attitudes and views of the student nurses because these might differ from those expressed by registered nurses.

Considering the influence that attitudes, knowledge and experience are thought to have on registered nurses interactions with the dying, it is pertinent to discover the level of knowledge and the way the student nurses feel about organ and tissue donation.

The results of this phase of the research will provide insight into the attitudes and knowledge of student nurses to organ donation and transplantation, at various stages of nurse education. Data generated by students, at the beginning, middle and final stages of pre-registration education, were examined for differences that may imply changes occurring over time. The results of this investigation, which took place in one School of Nursing in Wales, are presented and discussed now, beginning with details of the sample used in the subsequent analyses.

## **Final sample details**

Data collection took place when the selected cohorts were attending the education centre during the period Spring 1995 to Autumn 1996. Seven cohorts of students, enrolled on a full-time pre-registration Diploma in Nursing course, took part in the study. Numbers within each cohort varied with those at the beginning of the educational process being larger than those at the middle or end. All of the students, in each cohort, who were present of the day of data collection, agreed to participate, but, as can be seen by Table 7.1, not all of the cohort members returned completed copies of the questionnaire.

<b>Cohort</b>	<b>n =</b>	<b>Response %</b>
Group 1	21	49%
Group 2	26	54%
Group 3	23	76%
Group 4	30	88%
Group 5	12	66%
Group 6	29	88%
Group 7	11	61%
Total	152	

A reminder was given to each group approximately seven days after the questionnaires had first been distributed with limited success. The cohorts who were in the 'Adult Branch' stage of their training (groups 3,4,5, 6 & 7) demonstrated a high level of response whilst those at the beginning of their training were less willing, as can be seen by the response rates in Table 7.1. The reasons for this cannot be deduced from this study. The returned questionnaires were examined for completeness and none were discarded. Subsequently, 152 questionnaires were included for analysis.

An overview of the students' attitudinal results will be presented now.

## **Pre-registration student nurses' attitudinal results**

The scores for each attitudinal statement were summated. The eleven statements that corresponded to the positive aspects of the scale resulted in a maximum allocated score of 66, and a minimum of 11. The thirteen negative statements were allocated a maximum of 78 and a minimum score of 13.

The attitude scores, for the individual cohorts, are presented in Table 7.2.

<b>Cohort</b>	<b>Dimension</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>	<b>Min</b>	<b>Max.</b>	<b>N =</b>
Group 1	Negative	30.9	13.2	60	13	73	21
	Positive	54.9	5.4	22	44	66	21
Group 2	Negative	25.0	8.2	35	13	48	26
	Positive	57.3	5.6	22	44	66	26
Group 3	Negative	30.4	9.37	31	15	46	23
	Positive	51.0	8.7	35	27	62	23
Group 4	Negative	30.5	8.9	38	15	53	30
	Positive	54.9	5.8	23	43	66	30
Group 5	Negative	22.9	5.5	16	13	29	12
	Positive	58	5.1	16	50	66	12
Group 6	Negative	29.5	9.1	34	15	49	29
	Positive	53.8	9.3	45	21	66	29
Group 7	Negative	29.1	8.1	26	13	39	11
	Positive	51.4	10.7	34	31	65	11

Table 7.2 reveals that there is no clear pattern of socialisation effect when the mean scores are examined. The mid-term cohorts generated similar scores, with the exception being Group 5. This group scores lower negative and higher positive mean attitude scores when compared with the other mid-term cohorts. The two cohorts, Groups 1 & 2, surveyed during the first third of the pre-registration training, produced scores that were dissimilar.

The end-cohort scores were in line with those of cohorts at less advanced stages of training. However, the attitude strengths of this cohort had been measured earlier, when at the mid-term stage of training (see group 5), prior to participation in a study day focusing on organ donation and transplantation. Group 7 represents the scores several months after the study day. These were closer to those of the other cohorts, than Group 5', reflecting a change in attitude strength. Negative attitude strengthened, whereas positive attitude strength decreased.

All of the cohorts expressed relatively strong positive attitudes to organ donation and transplantation when one considers that the maximum score was 66 on this scale. All the cohorts were within 25% of the maximum score. The cohorts who had just commenced nurse training appeared to have similar attitudes to those at the middle and the end of their training.

There is little to suggest that exposure to patients, registered nurses, or to death, during this latter phase of nurse training, may be adversely affecting attitudes. However, such findings require further investigation, before any conclusions can be made.

### The influence of stage of training upon attitudes

Several weak correlations were identified in the data by using the Spearman's rank order correlation approach, between stage of training and specific attitudinal statements. However, the results have to be considered with a degree of caution, in view of the size of the end cohort of students. This cohort comprised of 11 students, which barely exceeds the minimum recommended by Polit (1996) to avoid Type II error. Polit advised that the sample should be greater than 10. The correlations are summarised in Table 7.3.

**Table 7.3: Significant correlations between specific attitudinal variables and stage of training**

Question/Statement	$r_s =$	$n =$
Donation sets a good example to others	.16*	151
Donation puts body parts to good use	.18*	151
Donation offers someone a better chance of being cured	.18*	151
Wanting to die whole	.17*	152
Donation is disfiguring	.198**	150

\*  $p < .05$     \*\*  $p < .01$



The first 3 statements in Table 7.3 focus on the beneficial aspects of donation. The results suggest that students towards the end of their training are less certain about some of the positive aspects of donation than colleagues who are less advanced in the course.

Concern over the negative aspects of donation may increase with stage of training. However, this finding is inconclusive and does little to suggest that experience mediate attitudes.

Nevertheless, the impact that thoughts and beliefs can have upon attitudes or on behaviour should not be minimised. The data from the students revealed a moderately strong association between negative thoughts of donation, such as being cut up making the person feel queasy, and unpleasant thoughts of death ( $r_s = .55$ ,  $n = 151$ ,  $p < .0001$ ). There was also a moderate association found between the unpleasant thoughts and personal donation intention. Those who felt strongly that donation made them feel queasy were less likely to sign a donor card ( $r_s = .49$ ,  $n = 151$ ,  $p < .0001$ ).

The exploration of the student data continued, to consider the effect that stage of training may have on knowledge levels.

## **Student nurses' knowledge of donation and transplantation**

Twenty-five statements designed to assess knowledge of donation, and transplantation, had the potential to generate a maximum score of 50 points, and minimum of 25 points, if all questions were answered. A correctly answered questions was awarded two points whilst an incorrect answer scored only one

point. A summary of the scores, generated by the student cohorts, is presented in Table 7.4.

<b>Cohort</b>	<b>Mean</b>	<b>Median</b>	<b>Mode</b>	<b>SD</b>	<b>Range</b>	<b>Min</b>	<b>Max</b>	<b>Mean % Correct</b>	<b>N=</b>
Group 1	31.5	32.0	27	4.9	17	21	38	63.0	21
Group 2	33.6	34.5	35	4.4	19	21	40	67.3	26
Group 3	33.9	34.0	38	5.9	22	22	44	67.8	23
Group 4	30.9	31.5	29	3.9	16	22	38	61.9	30
Group 5	33.3	33.0	32	5.4	17	24	41	66.6	12
Group 6	35.9	37.0	36	4.9	19	23	42	71.8	29
Group 7	37.0	38.0	38	3.5	12	30	42	74.0	11

The data in Table 7.4 suggests a tentative trend, for mean knowledge scores to improve with stage of training, although Group 4 & 5 are exceptions. The mean score, for each group, was found to be significantly different from every other group, using the One-way ANOVA test (Between Group  $df = 6$ ; Within groups  $df = 145$ ;  $F$  ratio = 4.29;  $p = .0005$ ). However, further testing using the LSD (Least Significant Difference) test, with significance level set at 0.05, failed to reveal that stage of training has any effect on knowledge scores.

Group 7's mean, median and modal scores are greater than the other groups. This cohort was the only one to have studied organ donation and transplantation as part of the curriculum. The findings support those generated by quasi-experimental exploration of the effect of education on student nurses' knowledge scores. Post-intervention testing revealed improvements in knowledge scores (Kent & Poland, 1996).

The questionnaire used to assess the students' attitudes towards organ donation and transplantation contained fewer attitudinal statements than the tool used with the sample of registered nurses. The students' tool contained just 24 statements assessing positive and negative dimensions of attitude, compared with 46

statements, as in the questionnaire used in the first study. Therefore, to facilitate comparison of the student and registered nurse data sets, the individual summated attitude scores, for the positive and negative dimensions, were converted into percentages. The results of the comparisons of attitude strengths are presented now.

## Comparison of student nurses' attitudes, with those of the registered sample

The converted attitude scores for both dimensions were compared and the results of the descriptive analyses are displayed in Table 7.5.

<b>Sample:</b>	<b>n =</b>	<b>Mean</b>	<b>SD</b>	<b>Range</b>	<b>Min</b>	<b>Max %</b>
Student - Positive	152	82.6%	11.5	68.2%	31.8%	100%
- Negative	152	36.8%	12.3	76.9%	16.6%	93.6%
Registered -Positive	326	65.6%	10.1	78.2%	16.7%	94.9%
- Negative	326	35.4%	9.6	54.3%	17.4%	71.7%

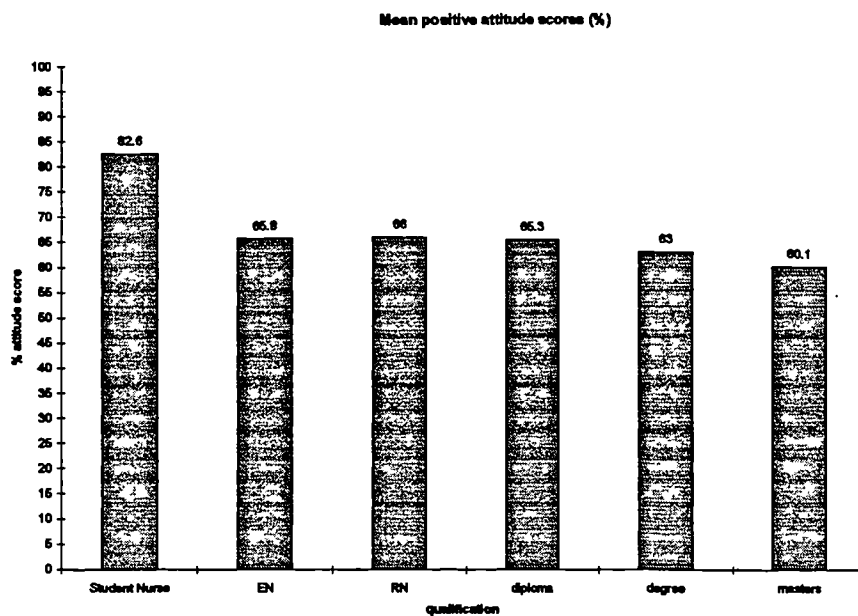
The students' mean percentage score, on the positive attitude dimension, was found to be greater than that of the registered nurses (see Table 7.5). When the range of percentages of the scores were examined, the students' minimum percentage scores were again higher than the registered nurses. The students also generated slightly higher percentage negative attitude scores, compared with the registered nurses' data set. The differences were not statistically significant.

The data sets were examined further, to explore the effect that level of qualification might have upon the attitudinal variables found to affect perceptions of ability to discuss donation among the registered nurse sample in Study One. The results will be discussed now.

## Attitudes and level of qualification

Figure 7.1 displays the positive attitude strengths of the student and registered nurse data.

**Figure 7.1: Mean positive attitude scores - student and qualified nurses.**



The data sets (student and registered nurses) were split by level of qualification and analysed for association between level of higher education and attitude strength. All of the students were studying at diploma level, whereas the registered nurses' qualifications ranged from the basic entry-level qualification, for the appropriate part of the UKCC register, i.e. RGN, or EN, to masters level. Students were classified, for analytical purposes, as having the lowest level of academic achievement, whilst those who had obtained a Masters degree, were awarded the highest status. Spearman's Correlation test revealed a strong association between level of education and positive attitude strength ( $r_s = - .567$ ;  $p < .0001$ ;  $n = 478$ ). This implies that the strength of positive attitude to donation decreases rather than increases, with academic levels of degree and higher. This finding contrasts with those of Parisi and Katz (1986). No similar association

was found, however, when negative attitudes and level of qualification was examined ( $r_s = .04$ ,  $p = .33$ ,  $n = 478$ ).

The student nurses, studying at Diploma level, reported stronger positive attitudes to organ donation and transplantation than the registered nurses who have been awarded the same higher education qualification. The diploma level registered nurses scored a mean percentage of 65.3, compared with the student nurses' mean score of 82.6%.

Registered nurses, who did not hold any additional qualifications, expressed slightly stronger positive attitudes to donation, than any other of the qualified categories, but these were lower than the student nurses'.

The exploration of the data moved, then, to examine, more closely, the students' knowledge of donation and transplantation, compared with that of registered nurses.

### **Knowledge: a comparison of students' and registered nurses' scores.**

The number of questions incorporated into the questionnaires administered to the students and the registered nurses differed. Therefore, the knowledge scores were converted into percentages to facilitate comparisons (see Table 7.6).

**Table 7.6: A comparison of percentage knowledge scores between student and registered nurses.**

	n	Mean*	SEM	Median	Mode	SD	Range	Min	Max
Students' % score	152	67.0*	.82	68.0	76.0	10.1	46.0	42.0	88.0
RNs' % score	326	69.8*	7.2	73.5	73.5	12.9	55.9	35.3	91.2
*t (369.2) = 2.52, p = .012									

The two-tailed t-test found a significant difference in the means of the two data sets. The mean percentage score of registered nurses (69.8%) was higher, at the 0.05 level, than that of the student nurses' group (67.04%):  $t(369.2) = 2.52, p = .012$ . However, the mean percentage scores were closer with a difference of less than 3%. The students achieved a lower median percentage score (68%) than the registered nurses (73%).

Correlation tests performed on the student data revealed a weak association between negative attitude and knowledge scores ( $r_s = -.17, p = .03, n = 152$ ). The registered nurses' data revealed no association between the two variables. This suggests that, for the students, negative attitude strength decreases as knowledge increases. The significance of this finding, on future practice, being that greater knowledge should enhance participation in the donation process by removing, or minimising, the threat to confidence posed by poor levels of knowledge.

A summary of the students' responses can be found in Appendix 12. However, since there were fewer statements for the students to respond to, compared with those given to the registered sample, only the responses to statements that were found in both questionnaires, i.e. the single questionnaire given to the students and the Organ Donation Knowledge Scale, given to the registered nurses, will be reported here.

Seven statements were used in the comparative analyses, encompassing the following subjects. Coincidentally, these were also identified, in Study One, as being factors that mediated perceptions of ability to discuss donation:

1. In the UK, does death have to involve asystole (the cessation of heart-beat)?
2. In the UK, is death declared before the organs are removed and the artificial ventilator (that maintains oxygenation) is switched off?
3. In the UK, can the doctor who certifies death of the potential donor be involved with the subsequent removal or transplantation of organs?
4. In the UK, are the procedures for determining brain-stem death well established?
5. Does the law, in the UK, permit the sale of organs?
6. Does the law, in the UK, require a request for organ donation to be made to relatives of all deceased patients?
7. In the UK, do any religious groups object to organ donation?

The results of the comparisons are summarised in Table 7.7. The data sets were examined for differences using chi-square test of independence. The choice of test was determined by the size of the sub-groups within the data sets, which prevented the criteria for parametric testing being fulfilled.

**Table 7.7: Comparisons of knowledge responses between, student and registered nurses, showing % correct and % incorrect.**

Question	Student		RN		Diploma		Degree		Test**	DF	Significance
	✓	✗	✓	✗	✓	✗	✓	✗			
1. Brain death and asystole?	48	34	61	38	72	24	75	24	$\chi^2 = 9.46$	4	p = .05
2. When is death declared - before or after retrieval?	58	42	63	36	60	38	62	31	$\chi^2 = 1.53$	4	p = .82
3. Impartiality of doctor?	31	66	45	53	39	59	34	59	$\chi^2 = 7.27$	4	p = .012
4. Well established bsd testing?	78	4	91	8	91	5	89	3	$\chi^2 = 1.64$	4	p = .802
5. Is sale of organs legal in UK?	82	10	78	21	73	25	76	17	$\chi^2 = 9.05$	4	p = .059
6. Is request compulsory in UK?	76	14	43	56	44	53	48	45	$\chi^2 = 63.6$	4	p < .0001
7. Any religious objections in UK?	47	13	60	40	58	38	43	52	$\chi^2 = 16.36$	4	p = .003

\* % do not total 100% in most cases: don't knows, and missing, responses not included in the table.  
 \*\* chi-square tests performed on actual responses, not percentages.



The results of the comparisons made will be discussed, beginning with the knowledge of asystole as a determinant for brain-stem death.

### Brain-stem death and asystole

This question examines respondents' understanding of what constitutes death and when death really occurs. The student group achieved a lower percentage of correct responses to this question, when compared with the registered nurses. This difference was found to be statistically significant (see Table 7.7). Table 7.8 shows the responses according to stage of training and level of education.

Group	Correct (%)	Incorrect (%)	Missing (%)
Student - beginner	25 (53%)	13 (28%)	9 (19%)
Student - middle	2 (45%)	35 (37%)	17 (18%)
Student - end	6 (55%)	3 (27%)	2 (18%)
RN/EN	146 (61%)	92 (38%)	3 (1%)
Diploma	39 (72%)	13 (24%)	2 (4%)
Degree	21 (75%)	5 (18%)	2 (7%)
Master	1 (100%)	0	0
Totals	280 (58.8%)	161 (33.8%)	35 (7.4%)

The findings reveal that a large minority of students thought that asystole is an essential determinant of death, thereby answered the question incorrectly, or did not answer at all. A greater proportion of the student sub-groups did not answer, compared with the registered nurse sub-groups. Consequently, it may be inferred that many of the students at all stages of the pre-registration course, and large numbers of the registered nurses, appear to be unsure about the use of brain-stem death testing to determine actual death of the person. A significant association was noted between students who stated correctly that asystole is not the key determinant of death, and students who stated correctly that there are well established procedures for determining brain stem death ( $r_s = .28$ ,  $n = 152$ ,  $p < .0001$ ).

The beginner stage results suggest that student nurses may be entering nurse education possessing a greater basic understanding of death, or brain-stem death, thereby reflecting awareness campaigns, undertaken by transplant co-ordinators, and voluntary organisations such as the British Organ Donor Society, which are targeting school age children. The percentage of correct scores for this sub-group was almost the same as that of the end-stage group, who had completed three years of their training. However, the results were still noticeably worse than those of the registered nurses.

The next statement relates to the timing of death and organ retrieval. The correct response is that death is always declared before the organs are removed and respiratory support withdrawn. The results of responses to this question are presented now.

#### **Timing of death and organ retrieval.**

There was no statistically significant differences found between the actual figures for correct and incorrect responses when the student and registered nurses data sets were analysed (see Table 7.7). This suggests that students' knowledge of this aspect of the donation process is almost as great as registered nurses. Education, during student nurse training, may have enhanced the end-stage cohort's knowledge in this area of the donation process. 81% of this cohort answered the statement correctly, compared with 56% ( $n = 79$ ) of the beginner, and middle, student groups; and 62% ( $n = 202$ ) of the registered nurses.

The next question focuses on the impartiality of medical practitioners, during the donation process.

**Involvement of the donor's doctor in the retrieval process.**

Over half, of all of the groups of respondents, answered this statement incorrectly, by indicating that medical practitioners involved with the care of the potential donor, are always, usually or sometimes, involved with the recipient. The correct answer was 'never'. There was a difference found between sub-groups' scores, which was statistically significant. Even so, over half of the RN group, which generated the greatest percentage of correct answers, indicated by their responses, that they were unsure about the impartiality of doctors. The student groups' percentage of correct answers was the lowest of all of the groups, but the differential was small.

There appeared, however, to be greater awareness, among the student and registered nurses, of the next issue, the procedures for determining brain-stem death.

**Procedures for determining brain-stem death**

The number of correct responses to this statement was high, indicating relatively good awareness levels of knowledge of the procedures used to determine brain-stem death. Not surprisingly, the student groups achieved a lower percentage of correct answers than the registered nurse groups, but the mean percentage (78%) was higher than anticipated. Only the end-stage cohort would have studied this issue during pre-registration nurses training, suggesting, again, that students may be entering nursing already possessing a satisfactory level of knowledge in this area of the donation process. Therefore, in the future, this may not be an issue that requires a high level of attention. However, further research is clearly indicated before any firm conclusions can be reached.

The next question focused on an aspect of the donation process that had received a lot of media attention in the UK over the last five years. The sale, and purchase, of organs in the UK, is illegal, even though some other countries still permit this behaviour, at the time of data collection (New et al., 1994). The respondents were asked to indicate if they believed that it was legal for a live individual to sell a kidney in the UK.

### The law and the sale of organs in the UK

Differences were found in the number of correct responses to this question when all of the sub-groups were compared but were not statistically significant (see Table 7.7). The students achieved a higher percentage of correct answers than the qualified groups (see Table 7.9).

Status of respondent	Correct Answer (%)	Incorrect Answer (%)
Student - beginner	37 (79%)	10 (21%)
Student - middle	78 (83%)	16 (17%)
Student - end	10 (91%)	1 (9%)
Registered	189 (78%)	53 (22%)
Diploma	40 (73%)	15 (27%)
Degree	21 (75%)	7 (25%)
Masters	1 (100%)	0

The end-stage cohort had studied this issues, albeit briefly, within the donation study day and this may account for this group achieving the highest percentage of correct responses once the possible outlier, the response from the nurse with the masters degree, is excluded from the data.

Continuing with the theme of legal issues of donation, the respondents were asked to indicate if they believed that health professionals are required, by law, to make a request for donation to the families of potential organ or tissue donors.

### **Required request in the UK?**

The difference in responses from the sub-groups was found to be highly significant, (see Table 7.7). The student nurses achieved the highest percentage of correct answers. The reason for this is unclear. The figures reflect, perhaps, the widespread lack of clarity surrounding this issue. The stance of having a legal requirement to approach relatives of a deceased person and discuss organ donation is not an uncommon one and is the system by which most of the states in the USA operate. However, in the UK, there is no legal requirement to do so, at present. If the system was to be changed, in the future, these findings suggest that the issues relating to required-request would need to be widely disseminated, particularly among the present day nurses. The need for education of information among the nursing profession, may decrease, however, as implied by the findings pertaining to the student group. Again further research is indicated.

The last of the statements focused on the issue of religion and organ donation.

### **Religious groups and donation**

The difference in responses, when the various educational levels were analysed, was calculated to be of statistical significance (see Table 7.7). However the figures reflect the level of uncertainty surrounding this issue. There was a large proportion of student nurses who did not respond to this question. These findings suggest that a large proportion of nurses at all stages of their nursing career are unaware of the guidelines produced by the different religious bodies in the UK, and believe, incorrectly, that most religions prohibit their followers from donating organs after death. There appears to be a need for more information to be given to nurses, to prevent incorrect information being conveyed to patients, or to relatives, in response to questioning about the donation process.

The Transplant Co-ordinators' Association (TCA) has produced an information leaflet for health professionals, to enhance their awareness of the support for organ donation in the UK, by all the major religious groups. However, the student data suggests that this issue will continue to be a focus for education and information for a number of years yet.

The implications of the comparisons made between the student nurses' and the registered nurses' responses are discussed next.

### **Implications arising from the comparisons made between student and registered nurses' attitude and knowledge scores.**

There was a strong support, in Studies One and Two, for nurses to be present during the formal request stage of that process. Their presence was thought to enhance the provision of psychological, and physical, support for the bereaved relatives and improve the communication of the issues being spoken about by the medical professional. Yet to meet the service demands, nurses are required to have an adequate understanding of the key issues involved in all major aspects of the donation process. The findings from this investigation indicate that deficits in knowledge continue to be identified. The comparisons made have helped to clarify the similarities and differences that exist between attitudes and comprehension of donation issues of the present day and the future nurses. The findings have implications for educators, and health care organisations, because their co-operation is essential if specific ways of enhancing knowledge, and confidence, among nurses, are to be developed and be deemed effective at meeting clients' needs in the future.

The student nurses' in the beginner and middle-stage cohorts, expressed stronger positive attitudes than the end-stage students. Although no firm conclusions can

be made, because of the risk of error and the absence of statistical corroboration, the findings raise the possibility that exposure to death, dying, and registered nurses' attitudes and behaviour, might pose an adverse effect on positive attitudes, as students' progress through their training. The data from Study One suggest that exposure to death, dying, and donation, can induce reflection on behaviour, including psychological reactions, towards a situation that is perceived as stressful to the family of the deceased, and to the carers. Student nurses generally have been less exposed to death due to their shorter professional record. Thus, the student nurses' views on donation and transplantation, particularly those at the beginning stages of training, may reflect, more closely, the views of the general public, than those of nurses. New et al. (1994) highlights the key findings, from surveys carried out by transplant organisations in the UK, that identify the high level of support for organ donation. Likewise this survey of student nurses' views on organ donation reveals the extent of the support for this procedure.

The measurement of negative attitudes, expressed by the student and registered nurses, indicated similarities in strength. Thus fears such as being pronounced dead prematurely, and being cut up, appear to persist among present day and future nurses. However, to imply that negative attitudes, within these groups of nurses, are more entrenched than positive attitudes, may be inaccurate due to sampling bias. The data produced by the cross-sectional investigation of student nurses, at varying stages of pre-registration nurse education, suggest that exposure to death and dying, and contact with nurses, who may be sceptical about participation in the donation process, may exert a negative effect on attitudes to donation.

When one examines the means of the beginning, middle and end cohorts, the pattern is suggestive of increasing negative scores, indicating an increase in the strength of the negative attitude dimension. However, the variance is small and not of statistical significance. The mean negative score at the beginning was 27.9, rising to 28.3 after almost twenty months of nurse education, and the mean

for the end stage group was slightly higher still at 29.1. These figures must be considered in relation to the maximum score that could have been achieved, 73 for the negative scale. Therefore, negative attitude strength, although rising lightly during training, remains weak.

Negative attitudes, reflecting fears and concerns about organ and tissue donation, were identified, in Study One, as having adverse effects on participation in the donation. The data from Study Three, appears to support this claim. When stage of training was examined for association with the other study variables, it was aspects of negative attitude that generated the strongest correlation. The statement 'organ donation leaves the body disfigured' was correlated, albeit weakly, with stage of training ( $r_s = .198$ ,  $n = 150$ ,  $p = .01$ ). Thus the implication is that strength of feeling over this issue increased as experience of nursing increases. This variable was also found, in Study One, to be significantly correlated with perceived ability to discuss donation. Therefore, the discovery of a similar pattern in the student nurse sample is important, as it identifies an issue that requires further attention. The sample sizes may have generated erroneous results, and more testing is required before any further conclusions can be made. However, it is a matter for concern, because such beliefs may have a detrimental effect on the nurse-patient or nurse relative interactions in the future. Findings from research exploring the factors affecting communications with relatives when making donation requests, suggest that negative beliefs are transmitted to the relatives and may adversely influence the decisions made. (Malecki and Hoffman, 1987; Perkins, 1987; Vernale, 1991).

For this reason alone, it is important that sustained efforts are made to allow nurses and other health professionals, to voice and discuss their concerns with experts, who can explain procedures and facilitate greater understanding of the mechanisms employed to minimise disfigurement of the donor. Without such opportunities for discussion, fears and concerns, that may be misplaced, can become fixed and subsequently, affect the attitudes of other health professionals.



Research using college students, undertaken in the USA by Shanteau et al. (1992) highlights the misconceptions, about organ donation, that appear to persist, or which are relatively resistant to change. The findings from the present research are supportive of Shanteau et al.'s assertions. Misconceptions of what might happen after death; during the diagnosis stage of brain death; and during the retrieval of organs or tissue, were uncovered in both the student nurses' and the registered nurses' data. Further research is required however, to assess the extent of these apparently deep-seated views, which appear to be resistant to change.

The comparisons between the student nurses' and qualified nurses' responses helped to identify the subjects that require further education, or information and those for which there appears to be an existing satisfactory knowledge base.

### **Educational issues for present day and future nurses.**

The responses of students and registered nurses, in Studies One and Three, identified several areas where the students' knowledge, in this area, appeared to be better than the registered nurses. Conversely, there were areas where the registered nurses appeared to be more informed than their student counterparts. Not surprisingly, the registered nurses did better, than the students, when answering statements that focused upon specific aspects of the donation process, such as the determination of death, the timing of death in relation to organ retrieval and the extent of the donor's doctor's involvement with any organ or tissue retrieval. However, this still leaves scope for improvement. The comparisons made in this chapter highlight the lack of understanding, surrounding some aspects of the donation process, evident among the present day nurses and those of the future.

It was interesting to note those areas of donation and transplantation in which the students did better than the registered nurses. The comparisons made in the data

indicated that this was more likely to occur with issues concerning the less technical or specific issues. The student group appeared to be much better informed about the legality of the sale of organs in the UK, and with the request aspect of donation.

Quite why the student group performed better in this area of the donation process, than the registered group, cannot be determined from this investigation. In the early 1990's, the sale of organs for transplantation purposes was made illegal by an Act of Parliament in the UK and the background to the case was widely reported by the media, including the professional nursing journals. Consequently, the registered nurses would have had similar opportunities, as the student nurses, to read about these issues. There is no evidence to support the supposition that the students have had any greater exposure to donation information than the registered nurses.

Responses pertinent to the item on religions and organ donation highlighted knowledge deficits among both groups of nurses. A low proportion of the groups answered correctly, which suggested a high level of uncertainty. As recently as 1995, the Muslim leaders in the UK issued a directive clarifying their position and informing Muslims that they can donate organs if that is their wish. Again, this was widely reported in the nursing and general press. Despite these efforts, at dissemination of the information, it appears that nurses' awareness of such directives is poor.

There was a high level of uncertainty, across all groups, surrounding the actual timing of death and the retrieval of the organs. The literature identified this as a potential barrier to donation (Perkins, 1987) and, yet again, it seems that such concerns might be redressed by having a greater understanding of the process. It might be possible for this increase in understanding to be achieved, relatively easily, through audio-visual presentations and discussion forums. Obviously more work is required before any associations can be determined.

Both groups appeared to be aware of the procedures for the determination of brain-stem death. The results reported here, nevertheless, suggest that being aware that such procedures exist, and accepting their accuracy at determining death of the person, are different issues. The media, television and newspapers, have highlighted organ donation and transplantation issues in the past, and there is evidence to suggest that such exposure has a positive effect upon levels of knowledge and understanding (Kent & Poland, 1996).

The effects observed in Study Three may be due, in part, to socialisation. However, it is more likely that the effects of increased education, and awareness, of donation and transplant issues, are being seen among the students who are entering nurse education today.

Subsequent informal discussion with respondents, both registered and student, revealed other methods by which information about organ donation can be obtained. Organ donation is a relatively rare event in the hospitals participating in this research project. When a donation does occur, it attracts attention, by being perceived as special event. The subject becomes topical, even for a short while, and both student, and registered, nurses, become caught up in the event. Discussions often ensue, at the time, among these groups of health professionals. Thus a donation itself can serve to raise awareness, but the duration of this heightened state is presently unknown.

The data, generated by the students' responses to the attitude and knowledge statements in the questionnaire, provide some very useful information for those concerned with nurse education. Study Three appears to be the first of its kind to have explored the attitudes and knowledge levels of UK student nurses, at different stages of pre-registration nursing education. Little is known about the coverage of organ donation and transplantation issues within the educational programmes undertaken by the registered nurses participating in this research. The qualified respondents indicated, in Studies One and Two, that they wanted more educational input, to improve their knowledge of such issues. Despite this

request, their knowledge levels were found to be good, with a mean knowledge score of almost 70%. Closer examination of the frequency distributions for the scores of the knowledge questions, revealed that the majority of nurses scored between 64% and 85%. Only 18% achieved scores below these figures. There appears to be a disparity, therefore, between the registered nurses' perceived and actual knowledge or understanding of donation issues.

The relatively small, but significant, difference between the mean scores for the student and registered nurses suggests three hypotheses. Firstly, that the registered nurses have had little, or no, more education, on this subject, than the student nurses. Secondly, that if education has been provided to raise awareness and knowledge of donation related issues, then it has not the desired effect. A third could be considered, and is a combination of the first two. Registered nurses may have had only minimal educational input about donation issues, and the methods of delivering the information has not engendered long-term retention of knowledge. The registered nurses' knowledge levels are only slightly greater than student nurses' who have, generally, only been exposed to the information that is given to the general public, to inform them about donation and transplantation issues. Questions need to be asked about the educational input, planned for the future, to ensure that it achieves its purpose.

A fourth should also be examined. The results generated by this research may reflect an increase in awareness of donation and transplantation issues among the general population. There is no supporting research evidence for this. However, it is one that should be considered carefully. If awareness of donation issues, among the general population, is improving, it follows that student nurses, entering the nursing profession, may well be better prepared for participation in the donation process than qualified nurses appear to be at present. Educational interventions could be devised, to build on pre-existing knowledge, targeting specific deficit areas rather than, as appears necessary at present, providing a vast coverage of donation-related issues. The medium through which such

information is communicated requires further investigation, however, to ensure optimal uptake, and retention, of information by health professionals.

Hare and Pratt (1989) found that unqualified health professionals felt less comfortable, when caring for those who are close to death, than the registered nurses in their study. Possible reasons for this included the difference in training for dealing with the physical, and psychosocial, needs of these patients.

Registered nurses may also have had more exposure to those patients who are close to death. Accounts and descriptions of the care required by the dying patient, and members of his or her family, continue to contribute to existing knowledge. They also help students, as well as novice nurses, to develop coping strategies, that can be utilised when faced with difficult situations.

Kiger (1994) argues that educators need to consider the educational goals for students, and clarify these, taking into account, students' lack of experience. She also implies that attention needs to be paid to the preparation and support of the student nurses to enable them to develop effective coping strategies that will help them deal with the emotional aspects of caring within nursing. Kiger implied that there is a danger of the student nurses losing the caring attributes and becoming 'hardened' professionals, if such support strategies are not addressed. Mood and Lewin (1979) stress that nurses, and other care givers, must learn how to become aware of their own fears of death, and dying, and the ways in which these feelings can be conveyed to others through the use of avoidance language. Avoidance does little to develop self-confidence. Instead it reinforces behaviours that neglect to meet the emotional needs of the dying and stifles communication that is, according to Ashworth, an essential component of caring (Ashworth, 1980).

Avoidance behaviours might inhibit the identification of patient's post-mortem wishes related to the donation of body parts. The results arising from Studies One, and Two, suggest that the issues of organ and tissue donation are avoided in a similar way that death and dying. It is important, therefore, that student nurses

do not adopt those norms and values that appear to be influencing the behaviour of the qualified nurses.

## **Chapter summary**

This comparative investigation has successfully identified informational and educational issues that require further attention, as well as those for which awareness is already good. The student nurses, in general, had relatively good levels of awareness of donation issues, despite their having had little or no formal education on such issues at the time of data collection.

Such findings suggest that, in the future, the levels of awareness among nurses, in the less specialised areas of care, may be enhanced if educational programmes are designed to focus on the identified deficit areas of knowledge, rather than the present diverse coverage. The implications of these comparisons, and the findings of studies One, and Two, will be discussed in Chapter Nine. Next, however, the limitations of the research design will be discussed.

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## Chapter Eight: Limitations of the Research

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### Chapter Overview

The contents of Chapter Eight focus on the limitations of the research, identifying issues that affect the adequacy and usefulness of the findings. The chapter begins by highlighting where unanticipated factors intervened and altered aspects of the project. Some imposed limitations on the investigation, whilst others tightened up the design, thereby ensuring that the focus of the project was maintained.

Limiting factors that could affect the uptake or acceptance of the findings by nursing, and other health professionals, are identified and the implications for nursing practice and patient care considered. The questions that prompted the original research ideas originated in practice and, ultimately, it is to practice that recommendations, arising from this research, should return.

As Black (1997) emphasised, research in nursing, as well as in other aspects of health care, should be a tool to develop practice. In turn, this should enhance the quality of patient care. In order to judge, however, the adequacy of the research, and before the findings are utilised in practice, the limitations of the research have to be acknowledged.

## **Intention versus reality**

From the outset of this investigation, the aims and objectives (see Chapter Four) were far-reaching and ambitious. The research questions were derived from professional practice and supported by the literature. The aims were developed to support those espoused by the Departments of Health, of England and Wales, to contribute towards achieving improvements in the services offered to patients.

Inevitably, unforeseen factors emerged to alter the research design. Some of these, it may be said, weakened the original design. For example, the failure to attract medical participation led to the absence of a key player in the investigation. However, as will be discussed now, this limitation appeared to have produced unexpected benefits that serve to enhance the quality of the data.

## **Limitations on the research design**

Factors emerged, during the planning and developmental stages of the project, which necessitated changes to be made to accommodate, or lessen, their impact. These factors included access to subjects; financial constraints; suggestions made by advisors in relation to research design; and resource issues. Unexpected intervening variables do not appear to be uncommon. For example, Chapple (1998) discussed the difficulties posed when trying to negotiate access to interview General Practitioners. The problems that emerged in that study were similar to those experienced during the present investigation. Gerrish (1997) also highlighted unforeseen problems, related to access issues and the difficulties facing nurse researchers when entering the field to undertake participant observation within an ethnographic study. These difficulties still require identification, because of their potential affect on the outcomes of the research.

The problems due to access included:



- Difficulty in obtaining access to medical practitioners.
- Refusal, by Heads of Nursing, for valid reasons, to allow access to staff in their hospitals.
- Delays in accessing details of nursing staff in some clinical areas.

It is pertinent to review these now, in view of the constraints that they imposed upon the research and its outcomes. The discussion begins with the potential limitations due to restricting the focus to nurses.

## **Restricting the focus**

Limiting the scope of exploration, to one health profession, affected the breadth of the investigation. Delays to the research process occurred whilst attempting to include members of the medical profession, particularly those who were involved in day-to-day patient contact, into the investigation. This resulted in the decision being taken to exclude them from the investigation.

The non-involvement of doctors imposed limitations on the completeness of the findings. Obtaining the views of both key groups of professionals, involved in patient care, would have permitted comparisons to be made, which might have indicated key areas where differences, and similarities, exist. Such information would have been helpful, particularly, when developing subsequent support initiatives. Taking a longer-term perspective, however, the limiting effect on the investigation is questionable. The subsequent focus of attention was upon nurses, and their views and reactions when contemplating the donation process. By focusing on one of the key players in the team, rather than diversifying to include a wider trawl, additional benefits have been derived.

Focusing attention on nurses appears to have generated feelings of worth among some of the participants or, at the least, feelings that someone is taking their

views seriously. During dissemination of the findings, responses were favourable, not just among nurses, but also professions allied to nursing such as health psychologists, members of the transplant organisations and also those involved with caring for the dying. By drawing attention to comments made by nurses, other nurses appeared to dwell on what has been said, and reflect on their own actions. One group of intensive care nurses was initially quite hostile when the findings were presented. They appeared to have difficulty reflecting on their feeling or reactions about participating in donation discussions. However, once they realised that fellow nurses, working in the same environments as themselves, experiencing the same critical illness situations, had generated the findings, they began to respond more favourably to the implication that the finding have on their practice.

Comments, made by other health professionals, also emphasised the advantages that can emerge when attention had been paid to a specific sample population. For example, at an international conference, in 1996, a social worker who specialised in caring for the recipients of transplanted organs and tissue, appeared to have difficulty comprehending that nurses would be willing to become involved in the donor identification and discussion aspects of the donation process. This highlighted the misconceptions that abound, pertaining to the scope of nursing practice. Traditionally, nurses were seen as handmaidens to the medical staff (Mackay, 1993), but that role is slowly changing. By presenting findings, generated by nurses, awareness of the extent of nurses' roles in patient care, and the limitations imposed either through culture, personal beliefs or other factors, is heightened. Thus traditional views may be altered through such dissemination. However, nurses may not be sufficiently adept, at present, at promoting these changes, particularly among other non-nursing professionals.

## **Accessing sites and samples**

It was acknowledged in Chapter Three that the regions for study were selected for their convenience for the researcher, as opposed to randomly identified.

Despite this the selection of data-collection sites, within each region, was randomised as far as possible. The final locations were determined by external factors, such as permission for access. The limitations imposed by the difficulties of accessing data-collection sites and samples cannot be ignored, since they reduce the generalisability of the findings for utilisation outside the immediate sample populations. However, steps were taken to deal with any problems, as soon as they emerged, to reduce the limiting effect on the investigation. Such actions were intended to ensure that the results obtained would be as reliable, and valid, as reality permits. These limiting factors, for each of the three stages of the research, will be discussed now.

### **Limitations related to the data-collection tool used in Study One**

The main limitation of Study One concerns the relatively unproven nature of the reliability and validity of the questionnaires used for data-collection. The variables examined key concepts, such as altruism, fears of disfigurement, and fear of mistaken diagnosis, in a number of differently worded questions, and the reliability of responses, assessed using Chronbach's alpha, was acceptable. However, further research is required before any conclusive statements can be made about the reliability and validity of the tools.

The using of questionnaires, particularly self-administered ones, to explore a complex aspect of human behaviour, has to be questioned, in light of the inconclusive nature of the statistical analyses in this investigation. The alternative choices, of methods of data-collection, were evaluated for their relevance or applicability. The conclusion reached, with the benefit of hindsight, is that given all of the circumstances, such as limited resources, geographical distances between data-collection areas, and time, no other method would have generated the same amount of detailed and useful information.

Surveys, as White and Brooker (1997) comment, have supporters and critics. The questionnaires used were lengthy and detailed, which almost certainly contributed to the low response rate (42% overall). However, given the prevalence of this methodology in health care research, and the competing work demands on nurses, the response rate was acceptable. The content of the questionnaires was closely scrutinised to ensure that only vital data was included. Cutting down the length of the questionnaires would have imposed additional limitations, such as reducing the amount of cross checking, of responses, to similar areas of knowledge, or attitude. Parahoo (1997) argues that this would demonstrate a lack of understanding of the enormity of the task of measuring and assessing attitudinal concepts. As White and Brooker (1997) indicate, there is no conclusive evidence supporting a correlation between shorter questionnaires and high response rates.

Efforts aimed at increasing the number of returns were employed, unsuccessfully. Letters and additional copies of the questionnaires were sent out to the sample members, and posters placed in the clinical areas, to remind nurses' to return their completed forms. However, in North Wales, these efforts generated just two extra responses. Consequently, no additional reminders were sent to the Leicestershire sample, and it remains unknown if such actions significantly affected the response.

Sampling resulted in 50% of the nursing population, which met the sampling criteria, being randomly selected from the lists obtained from the five hospital locations. Of these, over half did not respond. Therefore, Study One's findings were based on the responses of a small proportion of the sample population. Nevertheless, the computed minimum sample size, required for this investigation, was exceeded. Even so, this remains a major limitation of the research, and the implications are acknowledged. However, the results, from Studies One and Two, are informative and make a unique contribution to the body of knowledge.

Self-administered questionnaires create additional problems, mainly related to responses of participants. There can be no guarantee that the responses are a true reflection of the feelings, the opinions, or the knowledge, of those participating in the research. Conferring with others was not controlled for and, therefore, threatens reliability and validity. So too does guesswork, response bias, and for knowledge measurement, reading-up on the subject. These are, in reality, hard to avoid and it is recognised that these issues may have affected the responses of the sample members in Study One. However, balancing this, by more detailed exploration, was one of the reasons for adopting a combined, multi-method, approach to the research. Such an approach is not unproblematic. Redfern and Norman (1994) discuss these issues, together with the advantages of using different types of triangulation to explore phenomena. A combination of methods was proposed, by Denzin (1989), as a means of confirming validity. Yet other strengths, according to Redfern and Norman (1994), include overcoming bias from single studies, or single researchers; enhancing confidence in the results; completeness; enhancing understanding of complex social issues; and the addition of depth, or breadth, through divergence, to an investigation.

Problems also exist with the use of a combined approach. As Redfern and Norman (1994) indicate, a fuller or deeper picture, one of the reported advantages of this approach, may not be a truer reflection of events. Thus, the use of two health regions, although adding to the picture being created, has not necessarily created a truer reflection of the factors affecting nurses' ability to participate in the donation process in the wider population. The abilities of the researcher, together with the level of care that has gone into the planning and implementation of the research, will also affect the outcome of a combined approach (Redfern and Norman, 1994). There is a greater risk of error when more than one method is used, therefore, the choice of methods should be considered carefully. One should offset biases in the other, the result being a balance of strengths and limitations (Redfern and Norman, 1994).

The limitations, arising from Study Two, will now be discussed.

## Limitations associated with Study Two

Study Two, the qualitative exploration of nurses' experiences of, and reactions to, the donation process, required a different methodological approach, to that of Study One. After careful consideration of the issues raised by Redfern and Norman (1994), concerning the disadvantages of combining aspects of research design or methodology, interview, as a method of data collection, was selected to generate new data, and also help to support, or confirm the conclusions drawn from Study One.

Interview has its disadvantages, which can adversely affect the usefulness of the data. Those that are directly relevant to Study Two, are discussed here, beginning with the influence that the researcher might have on the responses given by the interviewees, which was a particular concern, particularly in the development and testing stages of the interview schedule.

I was acutely aware that I was entering the field with presuppositions that had developed during my own professional nursing career. Such potential influences should, according to Patton (1990), have been bracketed, or set aside, before progressing with interviews, if an eidetic phenomenological approach had been used. However the philosophy of the hermeneutic school of phenomenology was adopted and hence, my presuppositions became useful and valuable tools which aided comprehension of the recalled experiences. Admittedly, they still required identification, to facilitate the comprehension of the factors that influence the interpretative processes. They also served to provide insight and meaning to the investigation. However, there is a danger, when conducting one-to-one discussions, that the researcher can lead, or influence, the participant, thus reducing the trustworthiness of the data. As Parahoo (1997) indicates, it is difficult for the interviewer to probe objectively and fairly. This issue was closely monitored, during the pilot interviews, to minimise the incidence of

leading questioning. Being aware of the problem, and gaining confidence in the art of interviewing, helped to lessen the risk of this occurring during data-collection in Study Two. Close scrutiny of the nurses' interview transcripts suggested that, although a potential problem, it did not actualise in reality.

The semi-structured nature of the interview also imposed potential limitations on the investigation. It was difficult to remain passive, as a facilitator, during these conversations, particularly when the interviewee was aware that the researcher was also a nurse. Questions were often asked about my thoughts, or views, which required tactful redirecting, back to the interviewee, until the end of the interview.

The location of the interview also imposed limitations on the quality of the interview data. The participants were allowed to decide where it should take place. All of the interviews occurred either at home, or at work: one took place in the hospital canteen. There was the potential, in a few cases, for others to overhear some of what was being said. This may have limited the freedom of speech. These interviews tended to be shorter in duration, less spontaneous, and suffered more from interruptions, than those that took place outside the work place. Ideally all should have been performed in a quiet, comfortable setting, where confidential information could have been freely conveyed. Unfortunately, the reality of interviewing nurses, who were busy and had work commitments, meant that some ideals had to be relinquished. There was one instance when patient safety might have been compromised and so, the interview was halted, until a more appropriate time.

The limitations posed by sampling, method of data-collection, and the interviewer, within the qualitative domain, are acknowledged. Attempts were also made to control for bias. The validity of the findings has, yet, to be determined. Only feedback from readers of this research will determine the validity of these findings, as discussed by Oiler (1982). At present, verbal feedback, from qualified nurses who have listened to the reports of the findings,

appear to suggest that the experiences recalled are recognisable and familiar. Consequently, it is possible to comment that the limitations, discussed thus far, have not discredited the findings or the contribution that these have made to understanding nurses' behaviour towards organ and tissue donation.

The limitations of Study Three are discussed now, for completeness.

### **Limitations related to Study Three**

As with the other two studies in this research, there are limitations affecting the uptake of the findings in practice, involving the research design and the approach used for data collecting. Initial intentions were modified by reality during the progress of this study when time and resource constraints intervened to affect the study outcome.

Perhaps the most obvious limitation concerns sampling. Although the purpose was not to produce findings that had high generalisability, the convenience nature of the sample imposed limitations on the usefulness of the findings. This study was designed to elicit a synopsis of the similarities and differences that may exist, as a precursor to further, more extensive investigations. Although, a sampling strategy that used randomisation would have strengthened validity, its absence does not render the findings flawed. The design enabled student data, pertaining to the donation process, to be compared, with that of qualified nurses' for the first time in the UK, with satisfactory results.

There is a risk of the findings being inappropriately generalised. It must be stressed that the findings apply only to the participants of Study Three, and not to any other populations. No wider assumptions can, safely, be made from these results. However, within the context of the current research, the data generated



by this convenience sample is useful in that it provides further information about possible behaviour related to the donation process.

The design of Study Three imposes additional constraints on the future usefulness of the findings. Ideally, the design should have been longitudinal to allow one, or more, student cohorts to be followed throughout pre-registration training, with measurement of attitudes and knowledge taken at predetermined intervals. This would have facilitated assessment of socialisation, as a mediating factor, on the development of personal and professional attitudes and knowledge of donation issues. However, the length of the pre-registration programme exceeded the duration of the research. The design therefore, reflected reality rather than the ideal.

Another limiting factor concerns the reliability and validity of the questionnaire used for data-collection. This tool was developed specifically for this investigation, thus, reliability and validity have yet to be established. Liaison with other researchers who, in the future, will use the tool will be essential to provide feedback. The content can be supported by the literature and appears to be appropriate for measuring attitudes and knowledge of organ donation and transplantation. Since this is the first time the tool has been used, there are no determinants of external reliability. Internal reliability, using Chronbach's alpha testing, was satisfactory. The objective evaluation of this tool is encouraged and comments welcomed.

All of the issues, related to the disadvantages of using questionnaires to explore a subject that may be emotionally difficult, or sensitive, to some participants, apply here. Poor response rates, inability to guarantee the quality of the responses, inability to clarify responses, and the risk of response bias, all impose limitations on the adequacy of the findings. The extent to which these limitations will discredit the eventual findings must taken into consideration at the design and planning stages of a research project. After lengthy deliberation, it was concluded that the advantages of the methodology outweighed the limitations.

Nevertheless, steps were taken to minimise risk of bias. For example, the students were not given any prior information about the focus of the research to eliminate the possibility of the knowledge data being skewed by prior reading.

## Chapter summary

Ford-Gilboe et al. (1995) suggested that four issues, which are not paradigm-specific, are examined when reviewing the quality of research:

- Quality of the data
- Investigator bias
- Quality of the research process
- Usefulness of the study findings.

These issues were used to guide the evaluation of the strengths and the weakness of the present research, when considering its contribution to the body of nursing knowledge.

## Quality of the data

In terms of quality, the quantitative element of the research, i.e. Studies One and Three, has been assessed for reliability and validity. Internal reliability of the tools has been tested using Chronbach's alpha, and the results were satisfactory. However, further testing is required. The attitudinal-measuring tool, used in Study One, has, since the present research commenced, been requested for use in seven separate research projects, across the globe. Countries where these projects are located include the UK; Hong Kong; the USA; and Australia. However, no reports of the outcomes of these projects are, as yet, available.

The combination of methodologies utilised in the present research does not appear to have imposed limitations on the findings. Rather it has had the opposite effect. The interview method, in Study two, enabled superficial comments, made in Study One, to be explored further. Therefore, the use of qualitative methods enhanced the adequacy of the research.

## **Investigator bias**

There was less opportunity for investigator bias to emerge as a problem, during Studies One and Three, because of the minimal contact between investigator and sample members. However, the risk of this type of bias occurring during Study Two must be recognised. Ford-Gilboe et al. (1995) argue that interaction, within the interpretative domain, is inevitable and beneficial to the investigation. However, the presuppositions that the investigator brings to that investigation must be clearly identified, thus minimising interactivity as a limitation. From the outset of Study Two these were clearly stated.

## **Quality of the research process**

Scientific rigour, and the quality of the research, was considered throughout the research process. The research design did impose limitations. No attempt was made to control for extraneous variables. Such activity may have compromised the reliability of the findings, particularly in relation to potential response bias arising from the profile differences that emerged in Study One. However, Study Two enhanced the credibility of Study One data by providing opportunities for clarification, explanation and discussion of issues that arose in Study One. In addition, efforts were taken to enhance the validity of the interview data by returning to the participants. The concept maps developed from the interview transcripts were returned to the participants for comments about the accuracy and completeness of the process. There was a dearth of response, which could be interpreted two ways. Firstly, that participants agreed with the thought mapping

that was performed. Alternatively, the participants either disagreed, but did not feel able to comment, or, they failed to interpret the visual map of their conversation. Obviously the former conclusion is preferable.

## **Usefulness of the study findings**

There are factors that limit the usefulness of these findings. One of these is sampling. Although efforts to enhance the usefulness of the findings were made, when developing the sampling strategy for Study One, the randomisation employed does not wholly compensate for the purposeful selection of the health regions used for data-collection. Inevitably, this reduces the adequacy of the research. Caution must, therefore, be taken when considering the application of these findings to a population that differs from that of this investigation.

Despite these limitations summarised above, the quality of the research, and its contribution to the body of knowledge, is not compromised, to any great extent, by the real world. Whatever the choice of methodology, or research design, there are advantages and disadvantages that can be identified. Compromises are normal. However, the limitations should be, and have been, acknowledged, thus ensuring that informed decisions can be made about the usefulness of the research to practice.

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## Chapter Nine: Returning to Theory

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### Chapter overview

**A**t this point in the thesis, it is pertinent to consider Ajzen's theory of planned behaviour in light of the findings of the present research. The contribution, made by each of the three studies, to the advancement of nursing knowledge and scientific enquiry, will be detailed and discussed. This chapter completes the scientific process, in which the ideas, originating in practice, are investigated within the real-world, and then related back to practice. Such activity emphasises the links between theory, practice and research: each being essential pre-requisites for advancing nursing knowledge and improving patient-care.

## **Factors influencing nurses' perceptions of ability to discuss donation**

The reviewed literature revealed a wealth of research focusing on personal donation behaviour, as well as organisational and psychosocial barriers to donation (Gaber, 1990; Houlihan, 1988; Robinette and Stiller, 1985; Robinette et al., 1985; Soukup, 1991; Spital, 1991). These studies indicated that, of all the health professional groups involved in the process of organ and tissue donation, nurses were the most appropriate to inquire about donation wishes. Nurses were found to have the greatest contact with patients and relatives, during a stay in hospital and frequently inquired about sensitive, personal issues, as a normal part of their work (Carbary, 1987; Chan Mei-fung, 1996; Kiberd and Kiberd, 1992; Malecki and Hoffman, 1987; Matten, 1988; Matten et al., 1991; Shyr, 1993; Sofaer, 1995; Sophie et al., 1983; Sque, 1996; Stoekle, 1990; Weber, 1985; Wolf, 1990; Wolf, 1994).

Not only did these studies indicate that nurses were already participating in the care of potential donors and their relatives, they also hinted that there may be difficulties experienced when nurses engage in such care. Performing the essential physical, and emotional care, required by potential donors, appears to be accepted, by nurses, to be part of their job. However, such acceptance does not extend to the discussion of donation intentions. Few scientific studies have explored this concept, tending instead to focus on attitudes as indicators of behaviour. It is pertinent, therefore, to evaluate the findings, in light of the available literature, beginning with several of the key attitudinal studies.

### **Attitude towards donation discussion**

Attitude, the component of the theory of planned behaviour that incorporates affect and cognition is, according to Ajzen (1985), linked directly or indirectly to behaviour.

Attitudes, however, are one determinant of behaviour (Gross, 1987). Others include situational, societal, and experiential factors that mediate human responses to an object or phenomenon.

The strength of attitude to donation was assessed two-dimensionally, to determine the positive and negative dimensions. The data, generated by the qualified nurses in Study One, support this. This has been valuable because it facilitated the isolation of the positive attitudinal variables from the negative, which, consequently, determined the level of influence of each on participation in the donation process. At the outset of the research, it was hypothesised that nurses who expressed strong positive and weak negative attitudes to donation would be more likely to feel able to discuss donation issues with patients or their relatives. This, however, could not be supported. The strength of positive attitudes, independently or in conjunction with negative attitude, does not appear to be a key determinant for this behaviour, although respondents were found to view organ donation favourably, as indicated by the mean positive attitude score. Rather, it is negative attitude strength that has a greater influence on the intention to discuss donation.

When the negative attitude scores were assessed for association with perceived ability to discuss donation a mild relationship was discovered. This implies that, as negative attitude strength increases, there is a corresponding fall in nurses' perceptions of personal ability to participate in the donation discussion phase of the donation process. This fits with the findings of research that have explored obstacles to the availability of transplantable organs.

Robinette et al. (1985), who investigated the supply of organs for transplantation in Canada, found that health professionals' negative attitudes appeared to adversely affect donation-related behaviour. In 1996, Sque reported that negative attitudes remain significant mediators of behaviour. Data generated by Study One endorses this association. Fear of being declared dead prematurely, dislike of the thought of organs or tissue being removed, and other similar anxiety-provoking factors, continue to

instil doubt among nurses, even those working in the specialist units such as intensive care, where most organ donors are identified.

The deterrent effect that negative attitudes have on behaviour is well documented. Therefore, the attitudinal results that emerged from Study One were neither revolutionary nor unexpected. The enduring nature of this obstacle to donation behaviour is, however, an interesting concept. This attribute appears to be resistant to change. The responses from the student nurses, in Study Three, add credence to this conclusion.

The comparisons failed to identify a reduction in negative attitudes among future nurses, although there was evidence to suggest that positive attitudes to donation are beginning to change. In a separate study, the effect of educational intervention on attitudes and knowledge was examined (Kent and Poland, 1996). The findings suggest that traditional educational methods do little to change positive or negative attitudes to donation. Further research is required to support this, since the sample size and convenience nature of the sampling strategy imposed obvious limitations on the reliability of the findings.

Similarly resistant views and behaviour have also been observed in nurses' death-related behaviour. Avoidance of patients who are close to death was first noticed by Quint in the 1960's (1966, 1967). More recent research, by McClement and Degner (1995), found that avoidance behaviour continued to be observed. This is despite the inclusion of death-related subjects in many curricula for nurses', and other health professionals' educational programmes (Degner and Gow, 1988; Eastham, 1990; Hare and Pratt, 1989; Hurtig and Stewin, 1990; Kiger, 1994; Lugton, 1994; Manley, 1986; Moscrop, 1995; Youll, 1989).

Nurses' behaviour appears to be influenced by societal factors, as indicated by McClement and Degner (1995). The findings of Studies One and Two suggest that societal pressure, including that exerted by colleagues, may be a strong determinant



of behaviour. The implication of this, on donation-related behaviour, will be discussed now.

## **Subjective norms**

Subjective norms reflect, according to Ajzen (1985), the perceived pressure, exerted by society, to undertake, or avoid, certain behaviour. Taking, firstly, the perceptions of social pressures that arise from society at large. Many texts, focusing on death, and societal reactions to this inevitable stage of life, comment on western societies' reluctance to talk freely about death and dying. Sudnow (1967) was one of the earlier sources of reference used in the present investigation. Even now, it is still possible to recognise the behaviours that he observed. Today, death is not a social event. Few people die at home, surrounded by friends, neighbours, and family. The high incidence of deaths in hospital, hospices and nursing homes, has, consequently, excluded those people, other than immediate family, when a death event occurs. The younger generations in society are growing up within a death denying culture with no change in sight, in the immediate future. Thus such behaviour becomes self-perpetuating. The avoidance of death discussion has implications for the hospital setting. If death is not discussed within the wider society, it follows that broaching the subject in the hospital setting will be anxiety provoking.

The prospect of causing anxiety, by introducing death-related issues during the nursing assessment, was raised as a discussion point by several nurses interviewed in Study Two. There was perceived pressure to avoid discussion of death in the hospital, possibly because of taboo in the wider society. Thus this influence impinges on the behaviour of nurses within the micro society of the hospital. To mention death serves to introduce the realisation that life is finite. It forces the nurse, and clients, to face reality, and consider that life ends, at some indeterminate time in the future.

Health professionals have relatively high exposure to death and the dying when compared with the general population but, despite this, they continue to express

similar fears and anxieties related to death. The pressure, exerted by these members of the micro society of the acute hospital, exert an additional influence on behaviour. This phenomenon was evident by the comments made in Study Two. There appears to be strong pressure to conform to the actions of others. Behaviour, likely to provoke disapproval by peers, appears to be avoided when a choice is permissible. There is an assessment made, of the costs and benefits of the proposed actions, which affects future behaviour. Thus, if the nurse perceives that it is unusual for death issues to be discussed with patients or relatives, it follows that subsequent behaviour would reflect the norm. The nurse who breaks away from traditional behaviour, risks adverse reactions from peers, and the effect of this may be too costly.

The effect of other peoples' actions, or responses, is not a concept restricted to the theory of planned behaviour. This was also identified in the bystander effect theory, by Latané and Darley (1993), discussed in Chapter Two. Applying the tenets of this theory to the discussion of donation intentions one can recognise similar emergent patterns of behaviour. People are reluctant to take the initiative and act first because of the risk of disapproval by colleagues.

It is apparent that identifiable subjective norms produce a cycle of inactivity. The pressure for non-discussion of death, and death-related issues, exerted by the wider and the local population, deters the discussion of donation intentions in these societies. The non-discussion ethos impedes the free debate of donation issues, among health professionals, resulting in the suppression of personal views. Nurses, who should be working as part of a health care team to enhance patient care, are, instead, uncertain about the reactions of patients, relatives or colleagues, when the subject of donation is raised. The perceived costs of any such discussion outweigh any benefits that may arise, and, as a result, non-discussion behaviour proliferates.

The dominance of non-discussion of death, and its related subjects, in society is a phenomenon that cannot be easily displaced. The origins of such behaviour are deeply rooted. Issues such as traditional role demarcation, differentiate nurses from medical professionals, exerting an additional, indirect effect, on nurses' behaviour.

Breaking the cycle of non-discussion requires the nurse to firstly overcome societal taboos over death and dying. The next obstacle to be surmounted is tradition. Mackay (1993) writes of the difficulties, experienced by nurses, when trying to be innovative, and introduce change. These include: the resistance of other nurses to be accountable and autonomous practitioners; traditional views held by some doctors, that nurses should follow doctors' orders; and concerns of nurses that they might be overstepping boundaries of acceptable performance.

Future behaviour, it seems, is moderated by perceptions of peer reaction. A supportive culture, where free speech and transfer of ideas is encouraged, would facilitate the interruption of the inactivity cycle. Yet, where the views, and reactions, of colleagues are unknown, motivation for change is low.

The results of the present research suggest that internal and external factors moderate the level of control over the actions that are being considered. At the outset of the present research, there was little definitive evidence to indicate their composition. Therefore, by using an emergent design to explore this component of the theory of planned behaviour, it has been possible to suggest which mediators appeared to be most significant in determining donation related behaviour by nurses. These will be discussed now.

## **Perceived behavioural control**

The extent of control that a person may have over future behaviour is, as Ajzen and Madden (1986) indicate, difficult to measure with accuracy. Actual control over donation-related behaviour is almost impossible to measure because of the individuality of each situation. It is difficult to predict all of the factors that might intervene to alter the degree of behavioural control that a person has in the clinical area. Expertise and ability of nurses vary, so too do the organisational and clinical aspects of health care. Consequently, the internal and external loci of control will change, according to the specific circumstances presenting at that time. Control,

therefore, is limited, rather than complete. Thus it follows that the greater the belief that the behaviour can be performed effectively, with access to all necessary resources and opportunities, the greater the perceived level of control over the behaviour.

Internal factors that interfere with control over donation discussion are closely interrelated. Reluctance to become involved in the donation process appeared to be linked with lack of self-confidence, which stemmed, in part, from doubts about skills possession, lack of knowledge of the donation process, and concern that this discussion would add to the relatives' distress or anxiety. Negative attitude to donation, particularly fears associated with the act of retrieval of tissue or organs, appeared to further complicate the degree of control. These reinforced the disquiet arising from intuitive instincts, and provide the nurse with further justification for non-participation.

External factors also interfere with perceived control, and can be used to defend decisions made in relation to behaviour. Lack of time to discuss donation intentions, and the perceived inappropriateness of the behaviour, were interpreted as being external factors that interfere with control. These external factors had not been identified at the outset of the research and were not available for statistical analysis, highlighting, therefore, the need for further research.

The extent that external, and internal, factors are used as excuses, to avoid performing behaviour, perceived as being difficult, cannot be determined from these results. Nevertheless, they are similar to those identified as internal and external mediators by McClement and Degner (1995), influencing nurses' behaviour when faced with caring for the dying in the critical care unit. They found that nurses, who had knowledge deficits, in the area of death and dying, would be reluctant to participate in caring for the dying, especially when previous experiences had been unsatisfactory. The present research suggests that previous experiences, particularly those perceived as being bad, had a deterrent effect on future actions. Reasons given for classifying experiences as bad included: health professionals showing lack of respect for

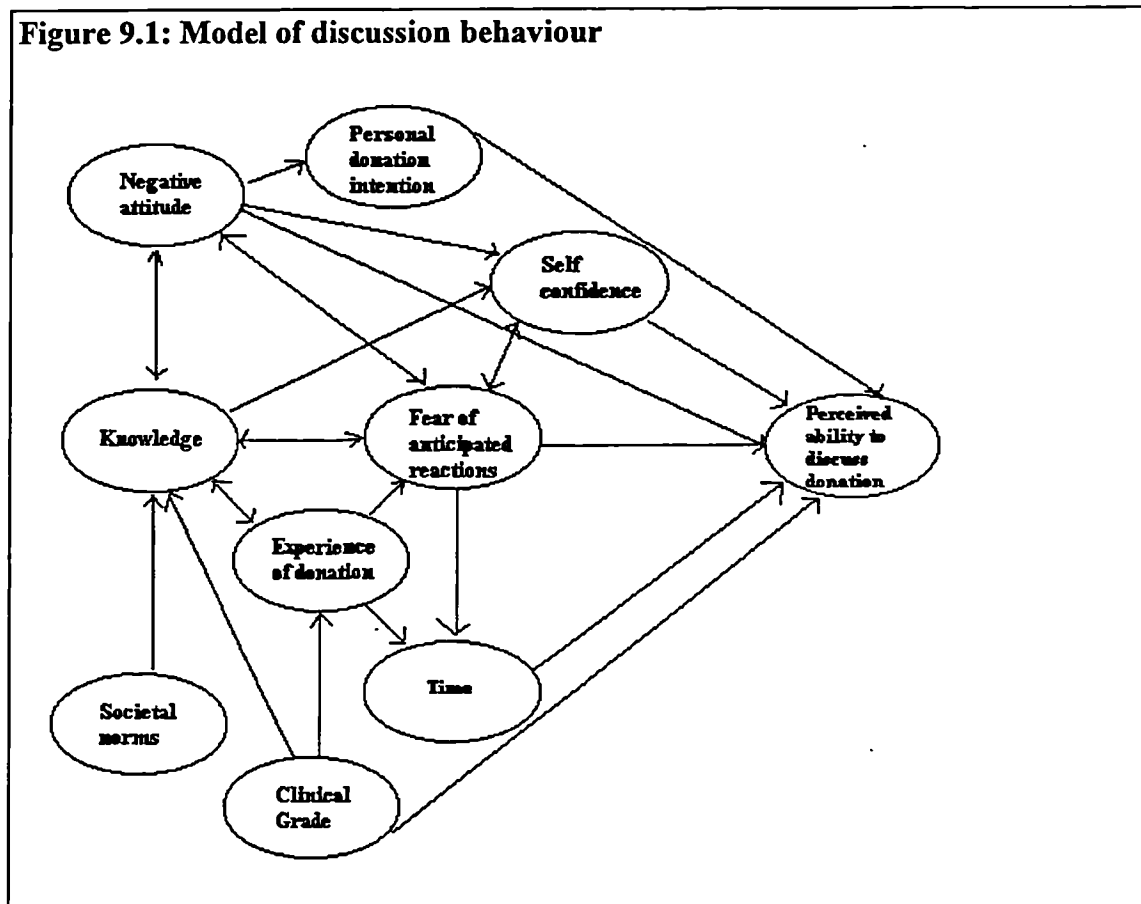
relatives; lack of respect for the patient; and engaging in actions that were not in keeping with the gravity of the situation.

The non-participation, or avoidance, behaviour of nurses does not appear to be dependent on clinical area of work. Nurses in the intensive care units were, statistically more likely to participate in the discussion of donation intentions, than nurses in other clinical areas. However, this finding was not corroborated by the interview data from Study Two. Nurses in all of the clinical areas expressed similar concerns over ability to discuss donation. The fear of anticipated reactions emerged as a strong deterrent for involvement in this aspect of the donation process.

The interrelationship of the different components of Ajzen's theory of planned behaviour cannot be wholly substantiated by the findings arising from the present research. However, the picture that emerges from the data is supportive of the framework. The interplay of variables, that emerged when a nurse contemplates participation in the donation process, particularly donation discussion, is illustrated in Figure 9.1, which represents modifications made to the theory of planned behaviour, in light of the research findings.

Each of the variables displayed in Figure 9.1 were identified, either by statistical analysis in Study One or as emergent themes in the conversations held with nurses in Study Two. They all interfere, to a greater or lesser extent, with nurses' perceptions of their ability to discuss donation.

Figure 9.1: Model of discussion behaviour



Further details of the proposed modifications to Ajzen's theory, are discussed next.

## Modifications to the theory of planned behaviour

Closer examination of the model reveals the two-way directions of some of the relationships. Take for example, the relationship between knowledge and attitudes, or knowledge and experience of donation. The design of the research limits the extent to which it is possible to determine which of the attributes has the primary role.

Attitudes, although developed through socialisation, as well as experiences and hearsay, may also be influenced by knowledge. Conversely, knowledge levels may be influenced by attitudinal variables. Similarly, experience of donation can influence knowledge, and knowledge can, in some circumstances, affect experience. The latter proposition is supported by McClement and Degner's (1995) model of avoidance behaviour. They found that exposure to the dying, when knowledge is poor, or when

understanding of the related issues is low, results in future avoidance behaviour. Experience alone may not suffice in determining future actions. The inference, arising from McClement and Degner's work, is that experience of the phenomenon, combined with educational support, albeit formal or informal, enhances the quality of that experience, and is more likely to be associated with positive behaviour in the future.

The research design prevented the statistical evaluation of the effect that societal norms, and external mediators of perceived control over behaviour, such as time, have on perceived ability to discuss donation. Nevertheless, the responses of the sample members, in Studies One, and Two, identified these as being key factors affecting future behaviour. A direct link, therefore, has been proposed between time and ability to perform the behaviour. During the interview stage of the research, the concept of time was raised by most of the nurses. Sufficient time was seen as essential prerequisite for any donation discussion to take place. Moreover, time was also given as a reason for non-discussion. The clinical areas were reported to be busy places, where time can be in short supply. There was apparent concern that, to introduce the subject of donation, and not be able to devote sufficient time to discussing the issues raised, would be an unprofessional act. Whether this claim can be substantiated in practice remains to be seen. In general, time should be found to discuss issues that are considered to be important, either by the patient, or by the nursing staff. Future research may find that time is being used as an excuse, to justify non-discussion of a topic that is perceived as being sensitive, and against societal norms.

Fear of anticipated reactions interacted with most of the identified attributes. Knowledge, experience, attitudinal factors, time and self-confidence, all affected the extent to which this appeared to mediate future behaviour. The strength of the interrelationships has not been determined, again due to the limitations of the research design. The fear of anticipated reactions emerged as a dominant theme during the qualitative analysis performed on the interview data and is a key component of the

proposed model. Attitudes, extent of knowledge, and societal norms related to death, all appear to affect the level of this fear.

The model suggests that, where negative attitudes, to death and donation, are relatively weak, and knowledge is good, the fear of anticipated reactions is reduced, and donation discussion is more likely to take place. Similarly, when prior experience of donation is perceived as being good, and self-confidence is high, the possibility of donation discussion occurring is enhanced. To date, these are propositions that cannot be substantiated but are strongly indicated as areas for further research. These have emerged from the data, the interpretation of which is enhanced by my own professional insight.

The literature reviewed in Chapter Two, identified the main psychosocial obstacles that affect health professionals' donation-related behaviour. One of these was the fear of adding to relatives' distress. Studies involving the relatives of organ donors, have consistently, negated the validity of this view (Pelletier, 1992; Pelletier, 1993; Sque, 1996). When the influence of this, apparently, unfounded but real, fear is considered, in isolation, it would seem an easy myth to dispel, thus removing an obstacle to the supply of transplantable organs. However, it is when the fear is considered within the context of its interrelationships with the other variables, as indicated in Figure 9.1, that the complexity of its influence on behaviour becomes apparent. This complexity may be one reason for the persistent dominance of this fear over behaviour.

The literature indicates the failure of dialogue to overcome this, seemingly, deeply rooted fear. The proposed interrelationships (see Figure 9.1), suggest that enhancement of self-confidence is required before the fear of anticipated reaction can be diminished. The nurses require reassurance that they possess the appropriate interpersonal communication skills, and knowledge, before they will consider undertaking the discussion of a subject that may raise the profile of death. It is as if the nurses, in this sample, believe that they will be seen to be failing, as professionals, if they have to admit that they do not have all the immediate answers to questions.



Although the additional variables have been detailed explicitly in Figure 9.1, I would propose that encompassing most, if not all, of these, is the concept of protection. Researchers have mentioned avoidance as behaviour that assists coping, when nurses are faced with difficult or unfamiliar circumstances (Quint, 1966; McClement and Degner, 1995). However, avoidance may be only one facet of the behaviour. The avoidance behaviour is undertaken to protect the nurse from feelings, fears, and other factors that have not been previously reconciled, or faced. This will be discussed further now.

## **Protection as a key variable in the model of discussion behaviour**

If each of the variables in Figure 9.1 are examined more closely, protection emerges as an explanation for their effect on perceptions of ability to discuss donation issues with patients or relatives. Take, for example, fear of anticipated reactions. When this theme emerged from the interview data, three sub-themes could be uncovered: fear arising from the reactions of relatives; from colleagues; and from self. The response of the nurse, to each of these, will depend on the level of protection that is perceived as being required to diminish the risk of harm to oneself. A subconscious evaluation is made of possible reactions that could ensue. It is unlikely that the nurse would feel confident to discuss a sensitive and difficult issue with relatives, patients, or colleagues, if the risk of an adverse reaction is too great. Therefore, the protection element is engaged, and the subject is avoided.

The Chambers dictionary (1988) defines protection as being “the act of protecting; state of being protected; and defence”. Protect means to “shield from danger, injury, change, capture, or loss”. The discourse, and the quantitative data, generated by this investigation, provided evidence of protective behaviours in keeping with the definitions above. The predominance of negative attitudes and beliefs, fears and misconceptions may be explained by the need for protection.

Experiences of donation may reinforce this protective element to behaviour. The nurses spoke of good and bad experiences, when recalling the donation process. Bad experiences were more likely to evoke non-discussion behaviour, to protect the nurse from a replay of the feelings, or actions that emerged from that bad experience. Good experiences, however, appeared to lessen the need for overt protection from these negative reactions, because the nurse has more confidence in personal abilities to deal with the emotions that arise from donation discussion.

Negative attitudes, and poor knowledge, may be used to justify non-discussion behaviour. Alternatively, they could also be used to protect the nurse, in the same way as has been detailed above. The development of these could be argued, however. Which develop first: attitudes, or the realisation that there is an individual need for protection?

Nurses' reported that the discussion of donation intentions might provoke an angry response. Fear of upsetting, or further distressing, relatives of the potential donor is not a new phenomenon, as the literature in Chapter Two highlighted. It appears to be a fear that transcends national boundaries, with support found in studies from the UK (Wakeford and Stepney, 1989) and North America (Prottas and Batten, 1988).

Nurses, however, should not find the anger response uncommon. As Smith and Hart (1994) observed, such reactions occur frequently in health care, and may be expressed by patients and patients' families. Nevertheless, in their research, Smith and Hart discovered that, when encountering anger, nurses became emotionally aroused. This arousal interfered with their ability to respond professionally to the situation.

Nurses were observed to respond to anger by connecting or disconnecting (Smith and Hart, 1994). Similar observations were made by Quint (1966), but she referred to the behaviour as avoidance. Smith and Hart (1994, p. 645) described disconnection as the "lack of ability to associate mentally, emotionally, and physically" with the source of the anger. This behaviour was initiated because the nurse felt threatened by the anger. They perceived that the anger was directed personally at them.

Similar comments, to those identified by Smith and Hart (1994), were made, by the nurses in the present investigation. Some felt that the anger was focused at them, rather than at the question that had been posed. This was perceived as being threatening to the nurse. Many of the concepts identified by Smith and Hart (1994) were also recognised in the nurses' recollections. 'Feeling attacked' made the nurse feel vulnerable; 'experiencing blame', at being the one to raise the subject that provoked such an emotional response in the relatives; and 'feeling powerless' because the nurse did not know how to respond, and felt out of depth with the situation.

The threatening situations were, according to Smith and Hart (1994), dealt with by engaging strategies that would minimise the threat. Again similarities emerged. If an angry response had been encountered previously, the nurses might, in subsequent encounters, avoid discussion of donation. Alternatively, they might feel the need to talk to other colleagues, to seek approval or reassurance that these angry responses are normal. A more positive strategy that appeared to be employed was rehearsing. There was clearly a need for opportunities that would permit preparation for the possible reactions to a donation request. These included role-play, observing others undertaking the behaviour, and discussing donation whilst others are present, to provide support, if needed. These defence mechanisms are not unique to donation discussion. According to Pilsworth (1993), they are employed in many facets of nursing to manage situations.

Whilst Pilsworth (1993) argued that, for some circumstances or individuals, distancing or other defence strategies might be beneficial by facilitating coping, the effect of these actions, if used inappropriately, may be less satisfactory. If protective behaviours are employed in every circumstance when the discussion of donation intentions is appropriate, the shortfall in availability of donated organs and tissue could worsen. In addition to this, the professionalism of the nurse could be called into question. Such actions are not in keeping with the requirement to act in such a way as to promote and safeguard the well being and interests of patients/clients (UKCC, 1992a).

This concept requires further exploration because, as yet, there is little supportive scientific evidence. However, it is an important concept that supplements the theory of planned behaviour, and which may help to enhance understanding of the motives behind behaviour of this kind. It is, therefore, pertinent to consider the implications of these findings for practice, and discuss what the future may hold.

## Implications of the findings for nursing practice

Throughout the present inquiry, attention has been focused on the role of the nurse within two crucial stages of the donation process: donor identification, and the discussion of donation intentions. This research has made a valuable contribution to the body of donation-related knowledge, by establishing the roles that nurses, in two regions of the UK, feel most comfortable at undertaking.

It has also been possible to identify those that are, currently, provoking anxiety among nurses. The following are roles that, according to the sample, should be performed by nurses:

- **Supporting** relatives of potential donors during the donation process. The supportive remit should also be extended to include colleagues, since this reflects a caring ethos, and adherence to the Code of Conduct (UKCC, 1992a).
- **“Paving the way”** to prepare relatives for the formal request stage of the donation process.
- **Donor identification**, by raising the possibility of donation with other members of the healthcare team.
- **Educating** colleagues, as well as patients and members of the public, to raise the profile of donation.

The thought of undertaking the formal request role, within the donation process, remains anxiety provoking. However, there was general agreement that providing support should extend to engaging in the formal donation request phase. The presence of a nurse, when the request for organ or tissue donation was made to the relatives was considered essential. In this way, the nurse is on hand to offer physical, and emotional, support to the relatives and moral support for the requester.

There appeared to be a sense of realisation, among the participants, that in time, the role of requester would be one that is undertaken by nurses. There are many aspects of the nurse's role that arouse high levels of anxiety. Inquiring about a person's religious affiliation, or next of kin details, may be anxiety-provoking for student nurses, until they learn effective coping strategies. As Kramer indicated (1974), when discussing the reason why nurses leave nursing, students can feel inadequate and frustrated when first faced with a new or unfamiliar situation or task. Similarly, it seems that nurses experience these feelings when they contemplate donation discussion for the first few times. However, the reluctance of the respondents to become the formal requester, at the present time, was moderated by the identification of factors that would help them to progress towards undertaking this role in the future.

The respondents indicated that the response of colleagues, to the proposed discussion of donation, adversely affect subsequent behaviour. Therefore, if the organisational culture was modified to facilitate greater freedom of expression of ideas, it might encourage donor identification and donation discussion. The nurses felt that they had to be sure that they had the support of colleagues, before proposing a patient as a potential donor, or before eliciting information about donation intentions. Nurses must encouraged to participate in decisions related to patient care. These are no longer the sole domain of the medical profession. The UKCC's requirement, that nurses act as the patient's advocate, promotes active, not passive, participation in clinical decision-making. However, as Mallik (1997) emphasised, lack of education, and training, in the role of advocate, can result in nurses being unprepared to take on this responsibility. Mallik also highlights the risk involved with the advocacy role,

and suggests that, even when morally the pressure to act is strong, the authority to act effectively as an advocate may be insufficient. Yet again, this demonstrates the intransigence of traditional roles and responsibilities.

There was concern about the possession of interpersonal skills, and nurses wanted more training to develop or refine the skills that they did possess. When the nurses were asked to comment on the appropriateness of health professionals to undertake this role, the quality of interpersonal skill emerged as a key determinant. There was little support for medical staff performing the role, because of their reportedly poor interpersonal skills, highlighted by earlier research (Grogan, 1979; Wakeford and Stepney, 1989). The message being conveyed, by the nurses in the present investigation, is that it is all right for medical staff to take on this role, even if it is done badly, but not so for nursing staff. Professional image appears to be a factor that further interferes with donation discussion decision-making.

The respondents' concern about alterations in image if it were seen that the nurses were unable to respond adequately to questions posed by relatives, was not wholly unexpected. However, this has not been identified in the literature as being an obstacle to the supply of transplantable organs. It may be that it is a phenomenon peculiar to the UK. Further research is required to ascertain the extent, and impact of this finding.

The findings from the present research, when considered alongside the evidence that has emerged from death education studies suggest that further education is needed in nursing, both at pre-registration and post-registration stages. Knowledge levels appear to increase with stage of training, and were found to be higher among the qualified nurses, than the student groups. However, educational programmes do not appear to have dispelled the well-documented myths, associated with the donation process, such as the timing of death, and the disfigurement aspects of donation. Moreover, these continued to be reported by the student nurse sample. My own observations, from attendance at these study days, permit me to reach the following conclusions:

- That, in general, these study days are didactic in nature, with little if any, audience participation.
- Opportunities for discussion of experiences or feelings are limited.
- They are well attended by nurses, suggesting that there is a need for further education, but few attempts are made to assess the duration of any knowledge or behaviour change.

These study days have little financial backing, and attendance is frequently without charge. Therefore, the methods used by speakers, to convey information, are resource driven. It is costly to organise educational days that utilise less didactic teaching methods, such as role-play, small group discussion and audience participation. However, the effect of these approaches, on attitudes, knowledge and behaviour are currently under evaluation by a group of psychologists, based in Liverpool and Manchester, within a large research project: the European Donor Hospital Education Programme (EDHEP).

The shortage of donated organs and tissue is also driving other research projects throughout Europe, which are collectively known as the Donor Action programme (Secretariat, 1997), designed to help hospitals improve their donation process practices, and intends to increase donation rates, through the provision of resources, skills and other resources.

Donor Action, EDHEP, and other associated initiatives draw on variables identified by Ajzen in the theory of planned behaviour. They also provide support for the interrelationships identified in Figure 9.1. However, the Donor Action programme appears, at present, to be in the early stages of development, and therefore not widely available. Consequently, educational interventions still need to be developed locally, to address the immediate needs of practitioners, and help them to fulfil the objectives of the national health gains. The data, generated by the present research, serves to identify the local needs, thereby enabling the targeting of specific issues that are pertinent to the sample population. These are, therefore, highly relevant to local

practitioners and, consequently, acceptance of the interventions is likely to be enhanced. Locally based initiatives are currently being explored, the progress of which is discussed now.

### **The development of local initiatives**

From the outset of this research project, it was anticipated that a strategy for supporting health professionals to participate in the donation process would be developed from the research data. No attempts were made to prejudge the requirements or contents of such initiatives, since it was important that these reflect respondents' needs. Suggestions made by the participants of the present research included:

- **A distance learning educational programme.** The need for enhancement of personal knowledge of donation issues, was acknowledged by the respondents. However, questions were raised about the resource implications of a widespread education campaign. As one ward manager quickly pointed out, priorities have to be set, and patient services has to come first, before staff development. Therefore, any programme would need to address the knowledge deficits, whilst at the same time, accommodating fluctuating service demands.

Distance or open learning is not a new initiative, and it has, during the 1990s, gradually gained in popularity. There are now a diverse variety of courses and learning opportunities in the field of nursing and health education. Distance learning is "a methodology that is primarily designed to enable effective teaching to take place even when the teacher and the learner are separated by distance. It involves the use of interactive learning materials as the primary source of teaching." (Robinson and Shakespeare, 1995 p4). However, conventional teaching methods may also be integrated within the programme, such as tutorials, and lectures, to offer further discussion opportunities.



The advances, in information technology, such as interactive CD-ROM programmes, and the Internet, need to be incorporated, where possible, into the package. It must be acknowledged, however, that distance learning will not suit everyone, nor is it appropriate for resolving all obstacles identified in the present research. Other suggestions made included:

- **Interpersonal skills training.** The effect that interpersonal skills can have on the outcome of a donation request has been well-documented (Carbary, 1987; Coupe, 1990; Franklin, Crombie, and Nicholls, 1996; Kiernan, 1987; Kiernan, 1995; Malecki and Hoffman, 1987; Malecki, 1987; Savaria and Swanson, 1995; Sque, 1996). The reports of the success of programmes, such as EDHEP, designed to help professional develop communication skills that are required for donation requests must be noted. However, the efficacy of such initiatives can only be truly determined through assessment of behaviour, as indicated by changes in the incidence of donation discussions. The use of reflective diaries in nursing practice is also advocated as a method of evaluating the impact that role-play or other interactive learning initiative may have on behaviour. Critical incident workshops may also serve a useful purpose by providing an outlet for discussion and reflection on practice.
  
- **Public awareness campaigns.** The interviewees felt strongly, that their willingness to participate in donation discussion behaviour would be enhanced through such campaigns. The fear of anticipated reactions was reportedly exacerbated by the perception that discussion of donation intentions would be unexpected, and thus increase patients' anxiety levels. This belief reflects the influence of subjective norms on behaviour. Donation and death are closely allied, and it follows that, where death is a taboo subject for open debate, so too is donation. The sample members proposed the development of awareness campaigns, informing the general public that the subject of organ donation would be discussed routinely during the in-patient admission process.

There was consensus, among the respondents, for greater openness in the discussion of subjects related to organ and tissue donation. There was a feeling that the influence of subjective norms, particularly the pressure imposed by society to avoid discussion of death and dying, should be minimised. However, it was acknowledged that such changes to societal behaviour would take time to achieve. Publicity campaigns appear to exert a transitory increase on the supply of donated organs and tissue, but this is not sustained once the campaign ceases (Warren, 1996a).

Self-confidence was identified by the sample members in the present research, as being a key determinant of future behaviour (see Figure 9.1). Each of the suggested measures, that have been presented here, are intended to provide support, be it educational or organisational. This support is intended to influence nurses' self-confidence and enhance perceptions of ability to deal effectively with expected and unexpected factors that may emerge during the planned donation discussion behaviour. A logical progression, from the use of experiential learning methods in the non-clinical environment, the success of which has been demonstrated by Sofaer (1995), is to transfer those principles to the practice setting. This has been experimented with in North Wales, with some success (details of this pilot project are presented in Appendix 13).

This initiative, together with national strategies such as Donor Action and EDHEP, reflect the importance placed on increasing the supply of donor organs and tissue. It is pertinent, at this point, to explore the recommendations for nursing practice, and future research, that emerge from the findings of this research.

## **Recommendations for education, practice and research**

The qualified nurses' and the student nurses' data imply that the prospects for an immediate change in donation discussion behaviour are unfavourable. Therefore educational, practice-based and research related recommendation are indicated, since

these reflect all of the facets of time: present-day, short-term future, and long-term future. These will be presented now, beginning with those for education.

### **Recommendations for education**

There has been greater input of psychology, sociology, physiology, and specific subjects such as death education, into the current pre-registration diploma in nursing curriculum, since the beginning of the 1990s. However, the findings from Study Three suggest that this has failed to make any significant difference to student nurses' negative attitudes or knowledge of donation and transplantation. Consequently, the first recommendation concerns the future of nurse education:

- Nurses do not appear, from these findings, to be sufficiently empowered, by present teaching methods, or curricula content, to respond positively to the changing demands in practice. There is support for nurses taking on the requester role in the future, but at present, self-confidence in ability is low. Greater use of experiential, and participatory, teaching methods, that allow skills to develop within a secure environment, is indicated. However, there are resource implications to this recommendation. Given the current trend towards large class sizes, the opportunities for role-play and group discussions are reduced. A more appropriate solution would be to integrate such methods within post-registration courses, where class sizes tend to be smaller. These students would also have the advantage of greater clinical experience, giving valuable insight, which pre-registration students generally lack.
- Further research is indicated, to evaluate the effect that changes to education have on actual donation discussion behaviour. To date, the research has focused on behavioural intentions, or perceptions of ability to undertake planned behaviour. Investigations should now progress, and further extend the boundaries of nursing knowledge.

The following recommendations focus on research and they emerged from the proposed interrelationships of the model of donation discussion.

### **Recommendations for research**

The first of these recommendations in this section is derived directly from the limitations of the present research:

- An evaluation of the conclusions, reached by researchers who have requested permission to utilise the questionnaires developed for data collection in Studies One, and Three, must be undertaken. Such activity will establish the reliability and validity of the tools, to measure attitudes and knowledge of donation and transplantation. However, the evaluation will also provide a comprehensive picture of nurses' activity in this area of health care, thus adding further to Nursing's body of knowledge.
- Further research is indicated, to establish the accuracy of the interrelationships proposed in Figure 9.1, in particular, that of protection. Dissemination of the findings from the present research suggests that nurses can identify with the key determinants, and with the links that have been proposed. However, to fulfil the principle of scientific rigour, additional investigations are essential. The key limitation of the present research, the method used to determine the sample populations, reduces the generalisability of the findings, and increases the risk that the findings are due to chance.
- Extension of the investigation of student nurses' attitudes and knowledge of donation and transplantation is required. The nature of the sampling strategy, i.e. convenience, rather than randomised, and the single case design (only students from one academic establishment were studied), calls into question the validity of the conclusions that have been reached. Comparisons made, between the responses of the qualified and student nurses, need to be further tested to assess the accuracy of the findings. A longitudinal design would be beneficial, to assess the effects that stage of training, and professional socialisation have on attitudes and knowledge.

- The student nurses were not directly examined on their perceptions of ability to undertake activities such as donation discussion. Therefore, within a longitudinal design, it may be possible to incorporate a measure that facilitates examination of this element of behaviour.

These recommendations have identified areas for future research. The list is not finite, and inevitably, others will be identified. The attention moves, now, to practice and the implications that the findings have on future behaviour.

### **Recommendations for practice**

The recommendations being put forward relate to Figure 9.1 and are intended to suggest ways of increasing the incidence of donation discussion by nurses.

- Nurses should consider ways of increasing their knowledge of donation issues. Lack of confidence appears to be exacerbated by poor knowledge, and both contribute towards non-discussion behaviour.
- Empowerment of nurses. It is pertinent for practitioners to consider how the ward culture can be modified, to enable the development of an ethos that encourages, and supports, multi-disciplinary participation in clinical decision-making. The UKCC has provided the authority for nurses to practice within the principle of autonomy, and requires nurses to act as patients' advocates. Adaptation is required, however, by nurses, to ensure that their practice develops in accordance with these directives, and the changing health care environment.
- Encompass caring as the central tenet of nursing. The concept of caring is reportedly a central tenet of nursing (Brykczynska, 1997b). Yet caring requires the

nurse to interact with the patient and the relatives, which incurs demands on time (Kitson, 1987). Time demands, at present, impose a deterrent effect on donation discussion behaviour. Nurses, therefore, must review the priorities of present day practice, and respond to changing needs. The quality of nursing care depends upon time being made available for patients and their relatives. Focusing solely on rituals, or procedures, must be eliminated from practice, if the principles of individualised care are to be anything other than just words. Organisational changes, at macro and micro levels, are required to ensure that nurses do indeed become, as Kitson advocated (1987), autonomous practitioners who are actively involved in decision-making, who can engender change situations and make valuable contributions to quality of life.

- Engender an ethos of openness in relation to death and dying. Death is an inevitable event, and one that nurses, working in acute hospital settings, are familiar with. Instead of avoiding death discussion, nurses have a duty to their patients, and to society, to identify patients' post-mortem wishes or death-related needs. Holistic care cannot be accomplished if one, inevitable, facet of life, is removed from the equation. Somehow the scientific evidence clearly indicating that donation discussion does not increase the relatives' distress, or increase patients' anxiety levels, has to be conveyed effectively to nurses. Greater awareness of death, dying, and the donation process is also required since this might help to boost nurses' self-confidence. However, someone still needs to talk to the patient, to determine, where possible, post-mortem wishes. The choice should be the patient's own, not that favoured by the health professional. Nurses do not always know what is best for the patient. The research carried out by O'Boyle (1994) emphasises the inaccuracies that can emerge when health professionals are asked to judge quality of life. Health professionals view patients care situations from a professional perspective. Patients view their life and care from a personal perspective. The two can be very different. Therefore, it is important that intuition, or gut reactions, do not form the sole basis for decision-making.

These recommendations are just that. They are proposals that have been developed after careful consideration of the evidence that is now available. Practitioners may choose to disregard the implications of the research, or they may decide to begin the process of actioning some, or all, of these recommendations that have been put forward for consideration.

Nursing, in the UK, is currently progressing through a period of change, in which traditional roles and activities are being expanded (UKCC, 1992b). Greater empowerment and autonomy is causing nurses to reflect on their practice and consider areas where skills, or knowledge, must be developed, to meet the changing demands. The national departments of health, in England, Wales, Scotland and North Ireland, have each identified aspects of health, or healthcare, that require specific attention in the immediate future. Disability, in particular, the services that are to be provided, by health professionals, to meet the needs of the disabled, were identified as target areas in Wales (Welsh Office, 1991). Organ and tissue donation fall within the remit of this health gain, since the transplantation of donor organs and tissue can alleviate disability and enhance quality of life. It is appropriate, therefore, for nurses to begin to consider how they can meet these requirements.

That notwithstanding, resolving the shortage of organs for transplantation is not wholly dependent upon nurses. There are obstacles that only government action can address, such as the legality of the donor card in conveying intentions and effecting subsequent behaviour. Others need to be addressed by educationalists. However, the nurse practising in clinical areas, where patients face death, either imminently, or in the longer-term, has a professional responsibility to offer the highest standard of care to those patients. To do this effectively, different facets of caring have to be utilised. Skill acquisition and expertise have to be developed. This process of professional socialisation is dependent upon education and practice. The organisational structure also needs to be optimised to ensure that quality care is provided, rather than being an unachievable aim. Research, too, has to be utilised, to ensure that practice is effective, and adaptable, reacting to advances in knowledge.

The discussion of donation intentions, and other aspects of post-mortem care, may not appear to warrant the highest priority for care when resources are limited. There may be other activities that require more urgent attention. However, for the patient, the priority may be very different. The decision to donate organs or tissue after death is not something that is made lightly. Normally, it is given careful consideration, and reflects deep personal beliefs (Bartucci and Bishop, 1987; Coolican, 1987; Hessing and Elffers, 1986; Prottas, 1994). Donation may not be the choice for everyone. Nevertheless, whatever the final decision, it is important that the patient's wishes are communicated and acted upon, minimising the risk that an incorrect decision may be reached.



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## Chapter Ten: Conclusion

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Given the aims and objectives, set out in Chapter Four, were to reach meaningful conclusions about nurses' willingness to participate in the donation process, the investigatory process has been successful. The theoretical framework served as a valuable guide, and the findings provide strong indications for theory and practice. They also offer hope for the future.

The case for investigating factors other than the willingness among the general public to offer organs or tissue for transplantation was put forward Chapters One and Two. The problems clearly lie with the health professionals and their willingness to participate in the donation process.

As Siminoff and Saunders-Sturm (1998) argued, recently, relatively little is known about why health professionals approach relatives to discuss donation intentions. Suggestions include lack of knowledge and concerns about the donation process (Younger et al., 1989); fear of upsetting the potential donor's family members (Savaria et al. 1990); time constraints (Prottas and Batten, 1988); and unfavourable attitudes towards donation and transplantation (Matten, 1988).

The timely nature of the inquiry is made explicit when statistics, compiled by the UKTSSA, are examined. Solid organ retrieval rates have been seen to vary over the past 5 years, with figures for Wales ranging from 16.7 per million population in 1992, to 18.0 per million population in 1995. In 1994, the rates peaked, at 21.2 per million population, before falling back to the 1995 figure cited (UKTSSA, 1996). Wales now has retrieval rates that are in line with the national average,

which was not the case when the research commenced. In contrast, the rates for the other health region, involved in this investigation, fell to below those for Wales: from 18.1 per million population, to 16.8 per million population over the same period.

A recent report in Hansard (16.3.98) highlighted the concern being expressed in the House of Commons about the falling retrieval rates and increasing kidney transplant waiting lists, which are costly for the NHS. Initiatives are currently being considered, by the Department of Health, which would serve to increase donation rates.

Tissue retrieval figures are almost impossible to evaluate because of the lack of any central database recording such procedures. However, the potential for increase, particularly in corneal retrieval, is immense, as demonstrated by figures from one hospital in North Wales (UKTSSA, 1996, 1997). Such retrievals have increased dramatically from less than 50 annually in 1994, to 168 in 1995. Figures for 1997 show a further increase; in excess of 200 retrievals. This has been effected through the involvement of the bereavement officer, who enquires about tissue donation intention when relatives collect the death certificate.

Descriptive and inferential analyses explored variables identified in the literature, as guided by the Theory of Planned Behaviour (Ajzen, 1985). Although the emergent correlations were, in the main, weak, several factors emerged that may have implications on donation rates in the future.

Factors found to mediate nurses' willingness to discuss donation included age; grade; clinical area; knowledge of donor criteria; negative attitude to donation; and concerns that stem from the UK's system of donation. However, the qualitative data, generated in the first phase of the investigation (Study One), introduced other issues into the investigation, which were also found within propositions of Ajzen's theory. The influence of subjective norms, such as the

responses of colleagues to donation discussion, and perceived control over the behaviour, were explored further in the second phase (Study Two). One of the main themes to emerge focused on the reactions of others or, rather, the fear of anticipated reactions. The links between these factors and donation discussion were highlighted in the model of discussion behaviour, proposed in Chapter Nine.

The model of discussion behaviour makes explicit the variables that emerge as key influences on nurses' willingness to participate in donor identification and donation discussion. Ajzen (1985) debates the dependence on others as a determinant of behavioural intention. Within the context of nurses' behaviour and the donation process, this appears to be closely related to other variables as indicated in Chapter Nine. The strengths of the associations, with the intention to discuss donation, are dependent upon personal attributes, and cannot be determined from this investigation. Even so, the fear of anticipated reactions was raised as an issue, by the majority of respondents who offered comments in studies One, and also in Study Two, and, therefore, cannot be ignored, or disregarded.

In 1989, Wakeford and Stepney found that nurses' behaviour was adversely affected when it was perceived that medical and nursing colleagues would not be wholly supportive of donation discussion. The findings from the present investigation confirm that such fears still exist. Closer examination of the general concepts, proposed by Ajzen (1985), and the specific issues put forward in Chapter Nine, exposed a further explanation for non-discussion behaviour: protection.

Protective behaviours may be behind the adoption of personal attitudes to donation and, in particular, donation discussion. Its influence may be reflected in the perception of others' behaviour, the subjective norms of the theory of planned behaviour. Shifting of blame occurs, which eases the perceived threat posed by the discussion of donation intentions. Non-discussion may, therefore,

be attributed to the unwillingness of others to undertake the behaviour. The blame for non-discussion is transferred from the individual to the significant colleagues, therefore lessening the perceived personal threat.

The concept of protection may also lie behind the internal and external factors, of the theory of planned behaviour, proposed by Ajzen (1985), and identified in the model of discussion behaviour in Chapter Nine. Ajzen argues that beliefs in personal control over the specific behaviour are related to the perceived possession of personal attributes needed to undertake the behaviour. That being so, the attributes identified by the respondents in Chapter Five, possession of which are considered essential if undertaking donation request, may be subject to the influence of protection. The nurses, who indicated that they did not feel able to discuss donation, with relatives, cited non-possession of these attributes as the reason for their decision. Such comments may be a means of self-protection. Non-possession of these attributes, equates to non-participation in donation discussion, hence, the risk of any perceived threat is minimised.

The extent to which protection behaviour is cognisant, is unknown, and would be difficult to determine accurately. Nevertheless, the effect of such behaviour has major ramifications for the future availability of donor organs and tissue and consequently, protection is a concept that must be explored further. The conclusions drawn by researchers who have studied protection behaviour in other settings, such as mental health (Smith and Hart, 1994) and oncology (Pilsworth, 1993) should be utilised. The identification of this concept raises the question of modifying the theory of planned behaviour to include this proposed determinant of behaviour. Future research may conclude that protection is a precursor to attitude, subjective norms and perceived behavioural control, as well as having a direct influence on behavioural intention.

Overall, the investigation suggests that participation in donation discussion was a duty that nurses did not feel ready to take on. However, roles that nurses' felt comfortable with were identified. These were classified as:

- Supporting relatives and colleagues, during the discussion of donation,
- Preparing relatives, and colleagues, for the potential for donation, but through discreet, rather than obvious, actions,
- Facilitating awareness of the need for donation among the general public, and among colleagues.

Mackay (1993) describes how nurses discreetly guide clinical decision-making by medical staff. The nurses, particularly in North Wales, appeared reluctant to be seen to be overstepping the mark, by assuming responsibility for donor identification and donation discussion. Despite the pressure imposed on nursing to progress and be seen as autonomous practitioners, the findings from this investigation suggests that, for sensitive issues such as donation and death, traditional practices continue to be adopted. Traditional role demarcations serve to protect the nurse from criticism or adverse reactions that are potentially threatening.

The data implies that, in North Wales, nurses' behaviour is determined more by traditional practices, in which decision-makers are identified by grade and age, rather than by personal ability, or personal attributes. Geographical and socio-historical factors may be mediating this effect. North Wales is more isolated, geographically, than Leicestershire. Consequently, there appears to be less job mobility, with nurses remaining longer in specific wards or clinical areas, than was observed in Leicestershire. The age of the sample population, in North Wales, was slightly older possibly reflecting the low levels of job mobility. Observations suggest that staff nurses, once in post, remain there for considerable time periods, thus restricting the influx of junior, younger nurses. Attitudes and behaviour may become fixed, and traditional practices, once established, become self-perpetuating through local socialisation.

Perceived, rather than actual, lack of knowledge together with practice, that reflects a more traditional, doctor-dominated culture, may be contributing to the

reluctance, of nurses, to discuss donation intentions with patients, or relatives, in North Wales. The concerns and the apprehension, revealed in Chapter Two (Hibbert, 1995), were echoed in the nurse interviewees' dialogue. This is significant because it enhances confidence in conclusions drawn from populations that differ culturally and organisationally. There is a wealth of research, emanating from North America, which may be highly relevant to the UK, particularly in light of the written responses reported in Hansard (1998). Although New et al. (1994) concluded that changes to the donation system, in the UK, are unlikely in the foreseeable future, circumstances, in particular, the rising demand for renal transplantation and the observed decrease in organ retrieval rates (UKTSSA, 1997), may intervene. Therefore, conclusions drawn from research exploring strategies for enhancing health professionals' awareness of the need for transplantation, undertaken in the USA, might be, safely, applied to the UK situation. The responses of nurses' to the donation process appear to be unaffected by the different systems of donation in use, a conclusion that could not be ascertained when this investigation commenced.

Whilst the present research has been extremely valuable in enhancing understanding of the deeper issues related to donation that mediate willingness and perceived ability to discuss donation, it has also highlighted some potential deficits that have implications for practice. Firstly, this investigation raises doubts over the efficacy of nurses to act as advocates for the patient. Personal attitudes, subjective norms, and other factors such as the timing of the discussion about death, and donation, appear to directly or indirectly influence nurses' perceptions of their ability to undertake such activity. Failure to elicit, and convey, wishes concerning post-mortem intentions places the onus for the realisation of donor potential, on the relatives. In effect, nurses are acting subjectively and reaching a decision based on their own, rather than the patient's, views. The ethics of such behaviour must surely be questionable. Research is required to uncover the extent of non-discussion of post-mortem intentions, and to explore, further, the reasons given by the nurses, in Study Two, for this behaviour.

The survey data suggested that assessment for donor potential was rarely undertaken unless a diagnosis of brain-stem death was likely. The data generated proved to be enlightening and emphasised the need for further research into the issue of non-assessment. The extent of this inactivity has only been hinted at, in the present research, however, it appears to be a major barrier, affecting the availability of transplantable organs and tissue.

A further issue arising from the research concerns the utilisation, and uptake, of research findings. Fears and misconceptions, related to donation discussion, persist among nurses. This indicates a need for further research. Variations in educational provision, covering the subjects of donation and transplantation, as well as the means by which the information is conveyed, within the courses that are available, must also be examined because, currently, they appear to be ineffective at reducing some of the fears about aspects of donation.

There is a further requirement for a research focus on the needs of nurses, in relation to organ and tissue donation, both now and in the future. There was an identifiable need for support, informational and organisational, to help nurses meet the needs of patients. Sque (1996) also emphasised this issue. The efforts of those involved in Donor Action and EDHEP, that are concerned with facilitating the development of skills, among health professionals, thereby enhancing the likelihood of donation discussion, require a wider audience. This investigation revealed a willingness, among nurses, for greater involvement in the donation process. Given appropriate support, the nurses indicated that they would be willing to undertake donation discussion in the future. Therefore, it is pertinent to harness such feelings, and identify ways of providing support, and motivation for nurses, to assist reflection on practice related to the donation process.

There are indications that behaviour is changing. Student nurses' appeared to have stronger positive attitudes to donation, than their qualified counterparts. Their knowledge, in some aspects of the donation process, was better than, or equal to, the qualified nurses. It may be possible for this to be encouraged during

pre-nursing, or pre-registration nurse education. The need for organ donation, and for the communication of donation wishes, has to be part of the awareness of all nurses. The effect that professional socialisation may have, on students' attitudes to donation, remains unclear. However, Davies (1993) suggests that role-modelling, in the clinical area, may be influential in determining student nurses' future behaviour. The effect of the prevalence of non-discussion behaviour, currently observed among qualified nurses, is not promoting the ideal image to student nurses. A longitudinal study, following a group, or groups, of students, and qualified nurses, over a period of time, would allow attitude, and knowledge change, to be evaluated.

The inconclusive nature of the quantitative study bears out the decision to use a combination of methodologies, from different paradigms, within the research design. Weinholtz, Kacer, and Rocklin (1995), discussed the use of qualitative methods to enhance the credibility of the quantitative. The inclusion of qualitative exploration has not salvaged the quantitative (Weinholtz et al., 1995) but, rather, it has added value and meaning to the investigation. The findings raise questions about the uniqueness of the donation experience. I would propose that this is perceived, rather than actual. The evidence suggests that the donation experience is no different to that of other deaths. However, unfamiliarity with brain-stem death, and the low incidence of organ and tissue donation, appears to raise doubts and concerns which, with additional education to raise knowledge and enhance awareness, will minimise the internal factors affecting control over behavioural intention.

The findings suggest that specific skills, knowledge, and other attributes must be acquired to effect nurses' activity in the donation process. This was also highlighted by Aroskar (1991), in response to Wolf's investigation of nurses' post-mortem care experiences. The phenomenon is not unique to the UK. Nevertheless, the skills, and the attributes identified in Chapter 5, require further investigation, to uncover the origins of such beliefs, as they are more than likely to be artefacts of our socio-cultural heritage.



Thompson (1994) proffered that the circumstances, and the location, of dying in present-day western society contribute to the way that health professionals' react to death and dying. She argued that the educational system engenders a reductionist approach to care, militating against empathy, personal interaction and extensive personal involvement. The data from the present research contrasts with Thompson's views. Qualified nurses were not afraid to interact with relatives, and they appeared to be empathic in their care provision.

Understanding the psychological responses to bereavement, however, might enhance this interactivity, and engender quality of death, as well as quality of life.

There is a distinct need for nurses to become more involved in decision-making in the donation process, even though this may be difficult to effect. Beyond the obvious reasons associated with higher donation rates, as Kennard et al. (1996) indicated, this can increase work satisfaction, and increase expertise, whilst at the same time increasing relatives' involvement in care, which may lead to increases in quality of care and satisfaction with service provision.

Kitson (1987) discussed the concept of standards of care in clinical practice, and stressed that nurses need to recognise that the information and advice given to others is never value free. She wrote:

“The essence of quality of care lies in how well we reflect and actualise those responses and feelings that are deepest in our being” (Kitson, 1987)

Nurses need to respect patients' wishes to provide quality care. Central to this thesis is the right of the patient to decide his or her own post-mortem outcome. This can only be achieved if nurses become more willing to assess patients' post-mortem needs, and elucidate wishes. If the aims of self-determination are to be achieved, the ethos of death denial has, at some point in time, to be altered. As

Mallik (1997) commented, for too long, nurses have made decisions based on their own values and wishes. She acknowledges that there are risks involved, when the nurse acts as an advocate, as was highlighted in the present research. To ease these fears, and minimise the influence of protection, on nurses' donation-related behaviour, education and preparation are required and a supportive, professional climate developed.

The findings have clearly highlighted the perceived needs, and deficits, related to cognition of the donation process. The fears and concerns, expressed by nurses, reveal the extent of the discomfort experienced when contemplating increasing involvement in an aspect of care that incurs emotional costs, risks and physical strain for the nurse. Despite this, the data made it apparent that some nurses have participated, actively, in donor assessment and donation discussion. Those nurses spoke of the satisfaction felt when the situation went well, and when the relatives were able to reach the decision that was right for them at that time.

This research has demonstrated the value of nurses, and the importance of knowledge, and confidence, during what is, in reality, an emotionally difficult aspect of care. Yet, as Clifford (1986) and Martin (1986) concluded, nurses' skills are important. It is the nursing staff who transform an unfamiliar setting of the ward, or ICU, into a place filled with hope, and compassion, if they themselves are supported.

In conclusion, therefore, it is appropriate to return to the thoughts of one of the nurses, without whom this investigation would not have been possible. Louise, a nurse from an accident and emergency department, summed up her views of what nurses can, and should, be doing in relation to donor identification and donation discussion. She proposed that the aim of care, when a patient first enters the hospital, must be to preserve or restore life. However, sometimes, all attempts at resuscitation fail, and it is appropriate to consider donation of tissue, or organs.

Louise suggested that the resuscitation councils should include, in the advanced life support resuscitation protocols, an addition to the traditional ABC (airway, breathing, and circulation). She wants donation added at the end. Initially, the immediate life saving measures of resuscitation take priority, until it is evident that such measures are unsuccessful. Then, life saving or quality enhancing attributes, of transplantation, are considered, through the assessment for donor potential. If suitable, and most patients are, for tissue donation, the relatives should be told about the death. At an appropriate time, they should also be asked to think about donation. There is no need for an immediate answer, because of the nature of tissue donation. Consequently, the relatives have time to consider the request, and discuss the patient's wishes. The following extract from her interview reflect her thoughts:

*“At an arrest, the line of thinking should be ABC + Donation. Carry out the resusc (sic), then if unsuccessful, consider donation. If this went into the ERC (European Resuscitation Council) guidelines, it would nationalise the policy and remove any local variations. This policy should be developed, not just for A&E, but for all areas to consider, when resuscitation is unsuccessful. This way you would know what to do. Just like in the ALS (advance life support) situation. You know, 99% of the questions, you should have that information. ”*

*(Louise, Sister, A&E)*

**“What is written without effort is, in general,  
read without pleasure.”**

**Samuel Johnson (1709 - 1784)**

**(Dictionary of Quotations, 1986)**

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## Appendices

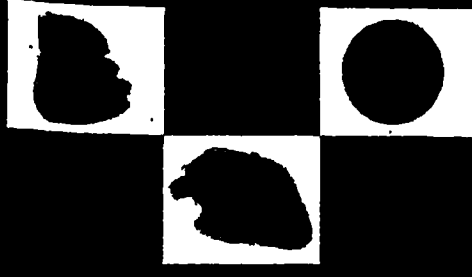
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## **Appendix 1: Criteria for organ And tissue donation.**

Each year thousands of individuals in the U.K. are affected with severe organ disease. Fortunately only a small percentage will experience complete organ failure and require dialysis or transplantation to survive.

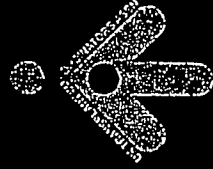
Over the last 20 years advances in surgical techniques, organ preservation and transplant immunology have made the transplantation of kidneys, hearts, lungs, livers and pancreas viable approaches to the management of various diseases.

As the long term results of organ transplantation continue to improve, more patients are referred for, or ask for treatment. There still remains, however, an inadequate supply of suitable organs and tissue for transplantation.



# Organ

donation &  
transplantation



Written and Produced by the UK Transplant  
Coordinators' Association



Information for  
healthcare professionals

### The cornea

- Corneal damage is a major cause of blindness. Thousands of people have had their sight restored by a successful corneal graft.
- Enucleation, can be carried out up to 24 hours after death.
- There is no age limit to corneal donation.

### The kidney

- Each year over 2,500 patients in the U.K. develop chronic renal failure.
- Transplantation is widely considered to be the treatment of choice for the renal patient allowing for a greatly improved quality of life.
- Every successful kidney transplant frees a dialysis space for another patient to commence treatment.
- The kidney graft survival rate is now over 85% in the first year.

### The liver

- Liver transplant operations have been carried out in the U.K since 1968.
- Indications for liver transplantation include congenital malformations, end stage chronic liver disease, fulminant hepatic failure, inborn errors of metabolism and primary carcinomas.
- The graft survival rate is now 75% for adults and 80% for children in the first year.

### The heart

- Cardiac transplantation commenced in this country in 1979.
- A heart transplant is considered for

patients with severe cardiac failure who no longer respond to medical treatment or who would not be suitable for conventional surgery. This group of patients has a life expectancy of six to twelve months.

- The graft survival rate is now 80% in the first year.

### Heart / lung

- The first clinical heart/lung transplant was carried out in the U.K. in 1984.
  - Indications for heart/lung transplantation include conditions leading to end stage primary lung disease or lung disease secondary to a cardiac problem.
- Such conditions include Eisenmenger's Syndrome. Atrial septal defect or ventricular septal defect.
- The graft survival rate is 75% in the first year.

### Heart valves

- Implanted human valves represent one of the most viable options for the patient in need of the replacement of one or more heart valves.
- May be removed up to 72 hours post circulatory arrest.
- Used mainly for children with congenital heart defects.

### The pancreas

- The ability to transplant the pancreas is one of the latest developments in transplantation. The pancreas can be transplanted alone or a combined kidney and pancreas transplant operation can take place.

- Patients suffering from Type 1 diabetes can be cured and the secondary complications of the disease halted.
- A combined pancreas and kidney transplant is particularly valuable for the small group of diabetics requiring renal replacement therapy.
- The graft survival rate is currently 45% in the first year.
- Following retrieval of any organ or tissue, the body is cosmetically restored so that the family may view the patient should they wish to.

### The criteria for organ donation

*The potential organ donor is a patient in whom brain stem death has been confirmed and who is being maintained on a ventilator. Common pathologies resulting in brain stem death include:-*

- Cerebral trauma
- Intracranial haemorrhage
- Anoxic brain damage e.g. following cardiac or respiratory arrest
- Primary brain tumour

*The following factors would exclude a patient from becoming a donor:-*

- Age more than 75 years. There is no lower age limit
- Malignant disease except primary brain tumour
- Major systemic sepsis
- Positive hepatitis B surface antigen test
- Positive HIV antibody test



## **Appendix 2: Brain stem death testing**

her relatives. So, as time went by, medical and nursing staff pressed for some means of resolving the plight of this small but significant group of patients.

At this time there was no legal definition of death. Hitherto, it had been diagnosed by irreversible cessation of breathing and the

action of the heart. But this clearly could not apply to cases where the heart continued to beat. To answer this need, neurosurgeons, anaesthetists and other medical specialists collaborated to draw up guidelines for diagnosing brainstem death. These incorporated simple tests (see panel) which

could be carried out at the bedside. In establishing these criteria the UK led the world in resolving a painful dilemma.

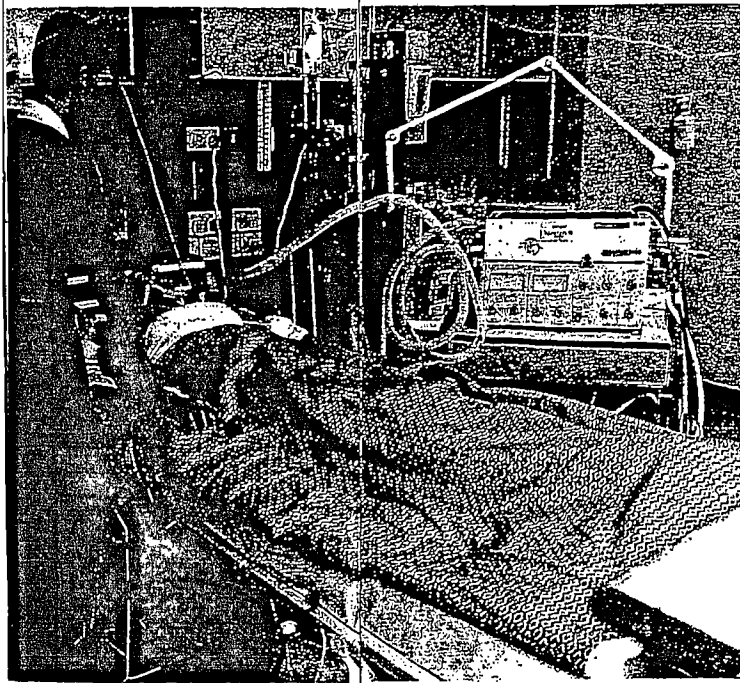
Today in Britain brainstem death tests are performed by two experienced doctors who are not involved in transplantation. As an additional safeguard the tests are repeated, usually within a few hours. The time of death is that at which the second set of tests is completed. It is at this point that the ventilator is disconnected if there is to be no donation.

Normally the question of donation will have been raised during the interval between the first and second set of tests. If donation is agreed, arrangements are made for the retrieval operation.

This is a difficult and poignant time for intensive care staff, who continue to care for the potential organ donor much as they did before death was certified. Medically, their concern is to maintain oxygenation of the tissues, to carry out routine hygienic measures, to prevent infection and to correct any fluid or chemical imbalances which may arise. Normally the patient is taken to theatre within a few hours.

In the case of the multi-organ donor, where several organs are to be removed, two or three surgical teams may be called in from various transplant centres. The retrieval operation, which may take up to four hours, is carried out with the same care and precision as an operation on the living patient.

Brainstem death is a bewildering concept for many people confronted with a body which is pink and warm and in which the heart is still seen to beat. Relatives often find it helpful to be able to see their loved one at rest, after the retrieval operation, either in a side-ward in the intensive care unit or in the hospital's chapel of rest.



## Tests for brainstem death

The following tests are performed only on patients known to have sustained irreversible damage to the brainstem — for instance, through head injury, haemorrhage, tumour or a failure of the oxygen supply to the brain. What is being tested are the various reflexes which signal life in the brainstem:

- Pupils do not respond to light
- No blinking when the cornea is touched
- No eye movement when ears irrigated with ice-cold water
- No gagging response to stimulus at back of throat
- No response to pain



No change in pupil size



No blinking



No eye movement



No gag or cough

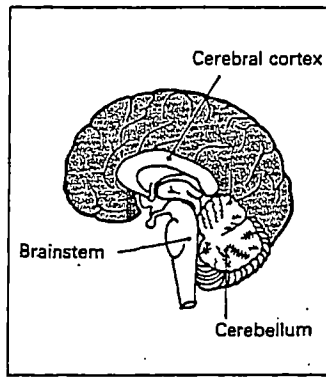
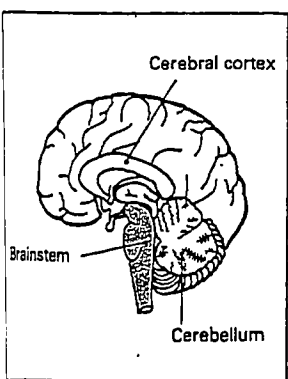


No grimace

If all these reflexes are absent, the ventilator is disconnected briefly to see if the patient makes any spontaneous efforts to breathe unaided. The ventilator is then re-connected and the tests are repeated a few hours later. If there is the slightest sign of life in the brainstem, the tests are discontinued. But if both sets of tests confirm that the brainstem is no longer functioning, death is certified.

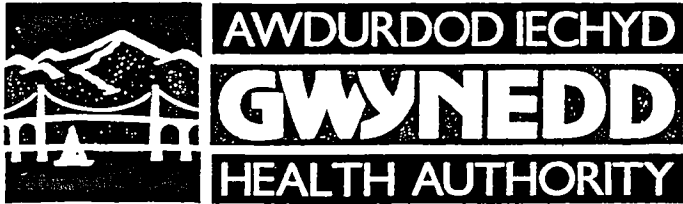
### The vegetative state

The persistent vegetative state (PVS) results from overwhelming damage to the cortex. So here it is the cortex which dies while the sturdier cells of the brainstem live on. Composed of right and left cerebral hemispheres, the cortex contains the so-called higher centres of the brain, responsible for thought and feeling and for the initiation of voluntary movement. PVS is unlike true coma in that the eyes are open for some of the time and a sleep/waking cycle is established. But the patient remains unaware of his or her surroundings, makes no purposeful gestures and never speaks. The vegetative patient may survive indefinitely — sometimes for many years — in a condition which many people regard as a living death.



From: *The Gift of Life*  
British Organ Donor Society

### **Appendix 3: Letter from local ethics committee**



Coed Mawr,  
Bangor,  
Gwynedd LL57 4TP

Ffôn/Tel: Bangor (0248) 370025  
Fax: Bangor (0248) 370214

Eich Cyf/Your Ref:

GOFYNNWCH AM/PLEASE ASK FOR

Ein Cyf/Our Ref:

.....Anne Wilkes.....

Est/Ext: .....2075.....

1 December 1994

Ms Bridie Kent  
Lecturer in Nursing Studies  
Health Studies Research Division  
University of Wales  
Fron Heulog  
Ffordd Ffriddoedd  
BANGOR  
Gwynedd

Dear Ms Kent

Further to your letter of the 22 November, I have today received confirmation from the Vice Chairman of the Gwynedd Research Ethics Committee that there is no need for you to submit the research proposal, as outlined in your letter, for ethical approval.

Yours sincerely

ANNE WILKES (Mrs)  
SECRETARY  
GWYNEDD RESEARCH ETHICS COMMITTEE

## **Appendix 4: Letters authorising sites for data collection**

Ysbyty Maelor Wrexham, Wrexham, Clwyd LL13 7TD  
(0978) 291100 Ffacs (0978)

Croesnewydd Road, Wrexham, Clwyd LL13 7TD  
Telephone (0978) 291100 Fax (0978)

Our Ref: MWD/JAD

11th January 1995

Bridie Kent  
Lecturer in Nursing Studies  
Health Studies Research Division  
Fron Heulog  
Ffordd Ffriddoedd  
BANGOR  
Gwynedd LL57 2EF


Dear Bridie,

Thank you for sending me the details relating to your proposed research and I must apologise for the delay in replying to you.

I have discussed your request with Mr M E O Jones, Director of Nursing, who is willing for you to approach members of staff in the Maelor to collect data for your research.

Please let me know when I can be of further assistance.

Kindest regards,  
Yours sincerely,



Maldwyn White Davies  
Nurse Manager, Manpower/Administration



DISTRICT GENERAL HOSPITAL  
**YSBYTY CYFFREDINOL DOSBARTH**

Ms. Bridie Kent,  
Postgraduate Research Nurse,  
University of Wales,  
Health Studies Research Division,  
Fron Heulog,  
Ffordd Ffriddoedd,  
BANGOR,  
Gwynedd LL57 2EF.

Ein cyf/Our ref: ECE/VAJ  
Eich cyf/Your ref:  
Dyddiad/Date 19 April 1995  
Wrth ffonio gofynnwch am/Ii telephoning ask for  
Mr. E.C. Edwards  
Est/Ext. No. 4140

Dear Bridie,

Please find listed below the names of the managers present at the meeting of the Nurses and Midwives Executive Committee that you attended on 4th April, 1995.

Mrs. Mair Roberts, Clinical Nurse Manager - Medicine  
Mrs. Lois Harrison, Clinical Nurse Manager - Surgery  
Mr. Carl Pierce, Clinical Nurse Manager - Ophthalmology  
Mr. N. Ramessur, Clinical Nurse Manager - Care of the Elderly  
Mrs. Jacqui Titterton, Clinical Nurse Manager - Orthopaedics  
Mrs. Gwenno Davies, Clinical Nurse Manager - Gynaecology

I hope that your research is successful and thank you for attending the meeting on 4th April, 1995.

Yours sincerely

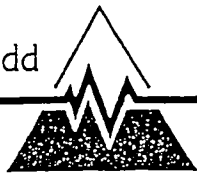
Mr. E.C. Edwards  
DIRECTOR OF NURSING





Ymddiriedolaeth Iechyd Ysbytai Gwynedd

Gwynedd Hospitals NHS Trust



Ysbyty Gwynedd/  
Gwynedd Hospital  
Bangor  
Gwynedd LL57 2PW

Ffôn/Tel: (01248) 384384  
Ffacs/ Fax: (01248) 370629

ich cyf / Your ref:

Gofynnwch am/Ask for:

4212

in cyf / Our ref:

RAJ/RP

26 April 1995

Mrs Bridie Kent RGN BSc  
Postgraduate Research Nurse  
Health Studies Research Division  
Fron Heulog  
Ffordd Ffriddoedd  
Bangor  
LL57 2EF

Dear Mrs Kent

Thank you for sending me a copy of your project report.

I am pleased that your project is developing well and should you have any problems please do not hesitate to contact me.

Yours sincerely

Mr R A Jones  
EXECUTIVE NURSE DIRECTOR



June 6th . 9.30 am  
Research meeting .  
Seminar Room, Ward 35  
Windsor Building  
Level 6.



THE  
**LEICESTER ROYAL INFIRMARY**  
NHS TRUST

Direct Line: 0116 258 5888  
Personal Assistant: 0116 258 5488

Mrs Irene Scott  
DIRECTOR OF  
NURSING & QUALITY

Mrs Beverley Dyson  
PERSONAL  
ASSISTANT

0116 258 5488

28 March 1995

Ms B Kent RGN  
Postgraduate Research Nurse  
Health Studies Research Division  
Fron Heulog  
Ffordd Ffriddoedd  
Bangor  
Gwynedd  
LL57 2EF

Dear Ms Kent

I am writing in response to your letter to Miss Wallam dated 27 February 1995. Firstly, may I advise you that Miss Wallam has now retired and I am her successor.

I was pleased to receive your request for The Leicester Royal Infirmary NHS Trust to participate in your piece of research and having taken the opportunity to discuss this further with some of my colleagues, I am delighted to advise you of the positive response. We would, of course, be interested in finding out a little more about the study and in light of this would like to suggest that you attend one of the research meetings that the Trust holds ever once a month.

If you feel able to do this perhaps you would be good enough to contact my Personal Assistant on the above extension and she will make the appropriate arrangements.

Many thanks.

Yours sincerely

IRENE SCOTT  
Director of Nursing and Quality  
1769IS/KJ

ADDRESS

Leicester  
LE1 5WW

Telephone  
116 254 1414

Facsimile  
116 258 5631



# LEICESTER GENERAL HOSPITAL

Nursing and Quality Assurance Directorate

Director: Mrs P M Lucas SRN, BA

Please ask for Ms.J.Geoghegan Ext. 4380  
Direct Line: (0533) 584380

21 March , 1995

Ms.Bridie Kent RGN BSc(Hons)  
Postgraduate Research Nurse (PhD Student)  
University of Wales  
Health Studies Research Division  
Fron Heulog  
Ffordd Ffriddoedd  
Bangor Gwynedd LL57 2EF

Dear Ms.Kent,

Thank you for your letter dated 27th February 1995 addressed to Mrs.P.Lucas concerning your doctoral research project.

I confirm that you can approach staff in all areas of the Leicester General Hospital, although the majority of patients benefiting from organ and tissue donation are cared for in the Surgical Unit. You may wish to contact the Senior Nurse Manager, Mrs.Lynn Holliday at the above address (Extn. 4662) before you approach staff in her Unit.

With every good wish for a successful completion of your project.

Yours sincerely,

Ms.Jacquie Geoghegan  
Asst. Director of Nursing &  
Quality Assurance.

Leicester General Hospital NHS Trust

Gwendolen Road Leicester LE5 4PW Telephone: 0116 249 0490 Fax: 0116 258 4666

Low environmental impact paper ☺ made from sustainable forestry

**Appendix 5: Letter authorising use of the Organ  
Donation Attitude Scale**

# RESEARCH TRIANGLE INSTITUTE

---

Center for Policy Studies

November 8, 1990

Bridia Kent  
20 East Mead  
Goldsworth Park  
Walking, Surrey  
England GU21-3BP

Dear Ms. Kent,

It was a pleasure talking with you this morning. As you requested, I am enclosing a copy of the Organ Donation Attitude Scale. The scoring key is also attached.

Most of the analyses were computed using a statistical software package titled SPSS. The cluster analyses was computed using a package titled BMDP. Many professionals today are using a software package titled SAS. Whichever you choose, or is available to you, will be satisfactory. The statistical equations are the same across packages.

I would indeed appreciate a copy of your study when it is completed. I wish you much support and success in your endeavor. Please do not hesitate or call me if you have any questions or comments. My home address and phone is as follows:

*176 - 100100K*  
Nina P. Rizzo  
105 Kirkfield Drive  
Cary, NC 27511  
(919) 859-9534 (Home)  
(919) 541-6309.

Sincerely,

*Nina Rizzo*  
Nina P. Rizzo

**Appendix 6: The modified Organ Donation Attitude Scale, used in this research.**

## ORGAN DONATION ATTITUDE SCALE

NAME:

AGE:

Please circle appropriate choice -

SEX :                      MALE                      FEMALE

QUALIFICATIONS :

RGN                      EN                      OTHER(please specify)

POST BASIC eg. E.N.B. 100, 124, etc. (please specify)

Diploma in Nursing / Health Studies

Degree in Nursing / Health Studies

Other (please specify)

CURRENT CLINICAL AREA eg. ICU, A&E, Medical ward, Surgical ward.  
(please specify)

ETHNIC ORIGIN

Caucasian  
Afro-Caribbean  
Asian  
Hispanic  
Other (please specify)

RELIGIOUS AFFILIATION

Protestant  
Catholic  
Jewish  
None  
Other (please specify)

Below are statements of beliefs about organ donation. Please read each one and decide the extent to which you agree or disagree. Indicate the strength of your feelings by selecting one of the following for each statement:

- Agree strongly
- Agree
- Agree slightly
- Disagree slightly
- Disagree
- Disagree strongly

There are no right or wrong answers; please state how *you* feel about the statements.



1. A person willing to donate is almost a hero.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
2. Organ donation leaves the body disfigured.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
3. Donating a body part would enable that part of myself to remain alive after my death.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
4. Organ donors cannot control which organs will be taken even when specified in advance.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
5. An intact body is needed for the next life.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
6. To donate one's organs after death is an act of charity.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
7. Organ donation interferes with an open-casket funeral service.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
8. By agreeing to donate organs at death, one sets a good example for others to follow.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
9. Deciding to donate one's organs at death adds extra meaning to life.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
10. Other members of my family would object to me signing an organ donor card.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly

11. Organ donation endows death with more meaning and worth.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
12. Transplanting organs is against God's will.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
13. Vowing to donate organs at death is a highly moral act.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
14. Medical school researchers who remove organs do not treat the body in a dignified manner.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
15. Vowing to donate organs at death makes one more respected and admired by family and friends.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
16. Preparing to become an organ donor brings to mind unpleasant thoughts of my own death.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
17. Extraordinary medical techniques will not be used to save the life of someone who has signed a donor card.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
18. Organ donation is a way of honouring God.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
19. Organ donation is a way to make up for past wrong doing.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
20. A person will be less likely to receive adequate medical care after signing a donor card.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
21. There is a good chance that doctors will be more likely to prematurely declare the death of a person who has signed a donor card.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
22. Hearing about people whose lives were saved after the receipt of an organ makes me think about the importance of donating my organs after death.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
23. Organ donation should not be considered because the body is sacred and has religious meaning after death.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
24. Donating organs at death is a way of putting some parts of the body to beneficial use.  
strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly



25. The surest way to bring about my own death is to make plans for it, like signing a donor card.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
26. The person who offers a part of his or her body for transplantation is making a really precious gift.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
27. It is unnatural to prolong life with body replacements.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
28. People have a moral responsibility to donate some of their body parts to people in need.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
29. A potential donor's death will be met by pleasure rather than by vigorous medical treatment by doctors.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
30. By agreeing to donate my organs after death, I am giving some people hope for survival.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
31. Promising to donate my organs upon my death makes me feel uncomfortable.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
32. Organ donors are special people.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
33. Organ donation benefits the whole of humanity.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
34. When I die I want the whole of my body to die with me.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
35. A person who intends to donate their body parts at death increases the likelihood that one will be pronounced dead even though one is still alive.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
36. Life is much too valuable to be cut short by a bad heart or kidneys, especially when organ donation can help to solve the problem.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
37. By signing a donor card, doctors might do something to me before I am really dead.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
38. A person with someone else's heart, eyes, kidney etc. is not the same person.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly

39. By donating a body part after my death, I could keep another person living.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
40. The thought of my body being cut up or taken apart after I'm gone makes me feel uneasy.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
41. By donating an organ at death, one can offer someone a better chance of being cured.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
42. Even if special precautions were taken to protect the life of a person who has signed a donor card, there is still a chance that their life will be taken to save the life of a rich or important person.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
43. Donating an organ after my death would make me feel proud of myself.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
44. When I die I want to be buried whole and with all my original parts.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
45. It is a shame to deny a person the organs he or she needs to keep the body functioning.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
46. Promising to donate is a genuine and unselfish act.  
 strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
47. How useful and effective do you think is the transplantation of the following organs? (Circle the appropriate answer)
- |    |               |                |           |         |
|----|---------------|----------------|-----------|---------|
| a) | Heart         | Very effective | Effective | Useless |
| b) | Lungs         | Very effective | Effective | Useless |
| c) | Eyes(corneas) | Very effective | Effective | Useless |
| d) | Bone-marrow   | Very effective | Effective | Useless |
| e) | Liver         | Very effective | Effective | Useless |
| f) | Bone          | Very effective | Effective | Useless |
| g) | Pancreas      | Very effective | Effective | Useless |
| h) | Heart valves  | Very effective | Effective | Useless |
| i) | Kidney        | Very effective | Effective | Useless |
| j) | Skin          | Very effective | Effective | Useless |

48. Are there any organs which you would never consider donating? (please specify)

If so, please gives reasons ?

49. Would you accept into your body a transplanted human organ if you needed one to survive?

Yes No Maybe

50. Would you accept an organ from a person of the opposite sex if you needed one to survive?

Yes No Maybe

51. Would you accept an organ from an animal if you needed one to survive?

Yes No Maybe

52. Would you accept an artificial organ, a machine, if you needed one to survive?

Yes No Maybe

53. Would you accept blood from someone else if you needed it to survive?

Yes No Maybe

54. Would you donate your own blood if asked to do so?

Yes No Maybe

55. Would you be willing to supply organs for transplantation if your surviving family was paid a good price for them?

Yes No Maybe

56. When you die, what do you want to be done with your body? Circle one -

Buried                      Cremated  
Frozen                      Given to research

57. Have you made out a legal will?

Yes

No

58. Please circle the appropriate response that you would make if you were asked to indicate your willingness to donate organs after death by signing a donor card -

I do not want to donate any of my parts after I die and I do not want to sign a donor card.

I am undecided about signing a donor card; I don't think I would like to donate my organs.

I am undecided about signing a donor card but I think that I would want to donate my organs.

I want to donate my organs and I would like to sign a donor card.

I have already signed a donor card.

59. At present, the UK system for donating organs after death is called 'opting - in' ; Would you support a change to this system? Please indicate your decision below.

**Opting - Out**

Yes

No

Don't know

Please give reasons for your decision.

**Required Request**

Yes

No

Don't know

Please give reasons for your decision.

Any other suggestions?

60. Have you ever had any personal or professional experience of the donation process? If yes, please state if it was in a personal or professional capacity.

61. Have you heard about the new NHS Organ Donor Register?

Yes

No

**Please turn to the Organ Donation and Transplantation questionnaire now, thank you.**

## **Appendix 7: The Organ and Transplantation Attitude and Knowledge Scale.**

**Organ Donation and Transplantation:  
Attitude and Knowledge Scale**

Hospital Name:

Area of work:

Grade:    D            E            F            G            H            Higher

Name (optional):

.....

Please answer *all* questions. All results will be kept confidential.  
Please circle the appropriate response below each statement.

.....

1. Organ transplantation is an effective means of treatment for patients with end-stage organ disease.  
Strongly agree    agree    undecided    disagree    strongly disagree
  
2. The widespread use of organs for transplantation will lead to a decrease in the quality of care for critically ill patients.  
strongly agree    agree    undecided    disagree    strongly disagree
  
3. Kidney transplantation offers many advantages over dialysis treatment.  
strongly agree    agree    undecided    disagree    strongly disagree
  
4. It is morally wrong to remove organs from one body and transplant them into another.  
strongly agree    agree    undecided    disagree    strongly disagree
  
5. Only heart, liver and kidneys can be transplanted at present.  
strongly agree    agree    undecided    disagree    strongly disagree
  
6. In the UK, it is legal for a live individual to sell one of his/her kidneys.  
  
                  Yes            No            Not sure
  
7. Heart transplantation is an effective means of treatment for certain people with terminal heart disease.  
strongly agree    agree    undecided    disagree    strongly disagree

8. In the UK, the family of a deceased patient who donates organs will receive payment for the donation.

Yes No Not sure

9. In the UK, health professionals must, by law, make a request for organ donation to families of all suitable deceased patients.

Yes No Not sure

10. Most religions prohibit organ donation.

Yes No Not sure

11. Liver transplantation is an effective means of treatment for certain people with terminal liver disease.

strongly agree agree undecided disagree strongly disagree

12. When patients are considered as potential organ donors, the hospital staff view them as donors and not as patients.

strongly agree agree undecided disagree strongly disagree

13. Organ donors are patients who have been declared brain stem dead.

always usually sometimes never

14. Removal of organs for transplantation is an unnecessary mutilation of the body of the deceased person.

strongly agree agree undecided disagree strongly disagree

15. Requesting organ donation puts an unfair strain on the families of deceased patients.

always usually sometimes never

16. Organs, such as the heart, liver or kidneys, can be removed after the donor's heart has stopped beating.

always usually sometimes never

17. A brain stem dead patient is not really dead until the heart stops.

strongly agree agree undecided disagree strongly disagree

18. Families of deceased patients will be offended if asked for organ donation

always usually sometimes never

19. Turning off the ventilator when a person is brain stem dead is mercy killing.

strongly agree agree undecided disagree strongly disagree

20. There are well established procedures for determining brain stem death.

strongly agree agree undecided disagree strongly disagree

21. The organ donor is declared dead before the organs are removed and the ventilator is switched off.

always usually sometimes never

22. The doctor who diagnoses and certifies the death of the organ donor can be involved in the removal or transplantation of the organs.

always usually sometimes never

23. Which of the following absolutely rule out tissue donation? Please mark a "X" by all that apply.

- |                          |                    |
|--------------------------|--------------------|
| a) Age 50+               | b) HIV infection   |
| c) Septicaemia           | d) Coroner's cases |
| e) Prolonged hypotension | f) Cancer          |

24. Which of the following absolutely rule out organ donation? Please mark an "X" by all that you think apply.

- |                          |                    |
|--------------------------|--------------------|
| a) Age 50+               | b) HIV infection   |
| c) Septicaemia           | d) Coroner's cases |
| e) Prolonged hypotension | f) Cancer          |

25. Please estimate for each category, the number of patients who are awaiting a transplant in the UK by placing a circle around the appropriate figures.

a) Kidney	2000 - 3000	3000 - 4000	4000 - 5000	
b) Heart	50 - 100	100 - 200	200 - 300	300 - 400
c) Liver	50 - 100	100 - 200	200 - 300	300 - 400
d) Lung	50 - 100	100 - 200	200 - 300	300 - 400
e) Heart/lung	50 - 100	100 - 200	200 - 300	300 - 400
f) Cornea	<100	100 - 500	500 - 1000	1000 - 2000 >2000

26. Do you personally intend to leave your organs for transplantation?

Yes No Not Sure

27. Would you donate the organs of a deceased family member?

definitely depends on the circumstances unlikely no

28. Have you ever cared for person who became an organ or tissue donor?

yes no



Please answer if applicable -

29. Have you ever approached a family for consent for organ and/or tissue donation?  
Yes (please state tissue, organ or both) No

30. Would you personally feel able to approach a family for consent for organ or tissue donation?  
Yes No

please give reasons :

31. Who do think is the most appropriate person to discuss organ or tissue donation with the family, and why? Please write your comments in space below:

32. How frequently are terminally ill or deceased patients assessed for tissue and/or/ organ donation suitability in your ward?  
Always Usually Sometimes Never

33. Does your hospital/ward have written protocols for organ and tissue donation?  
Yes No Not Sure

34. If protocols are written, do you feel that these provide adequate guidance for medical and nursing staff?  
Yes No  
Please give reasons

35. Please write any comments or criticisms you have concerning the current approach to organ and tissue donation. Continue on a separate sheet if needed.

I would like to discuss in more detail, on an individual basis, issues related to organ and tissue donation.

Please indicate below if you would like to participate.

No, I do not want to participate further.

Yes, I am willing to be contacted about further participation to discuss my thoughts and feelings about organ and tissue donation.

Please leave your name and telephone number and I will contact you within the next few months.

Name

Telephone number

Many thanks for sharing your feelings and thoughts with me. I would like to stress again that all information given will remain confidential. Your responses will be of great value in increasing our understanding of donation issues and in improving the service given to patients, their relatives and to the nurses caring for them.

If you would like any information about organ donation please write to me at

Health Studies Research Division

Fron Heulog,

Ffriddoedd Road

Bangor, Gwynedd. LL57 2EF

or telephone your regional transplant coordinator.

Yours sincerely

Bridie Kent.



Thursday, October 25, 1990

Mrs. B. C. Kent  
20 East Mead  
Goldsworth Park Walking  
Surrey, England  
G21 3BP

**College of Medicine**  
Department of Surgery  
956 Court Avenue, Memphis, TN 38163  
(901) 528-5909

Dear Mrs. Kent,

I am enclosing a copy of the survey that we used as the origin of the research paper published in Transplantation Proceedings. I am happy for you to use this survey for your thesis and at the same time I would be very happy to collaborate with you in any future publications or research regarding that.

Please note that this survey has a large number of questions that would apply only to the United States' rules, regulations and transplant experience. I would suggest that you change these to questions that relate to the U.K.'s experience and laws regarding transplantation. If you have further questions, please do not hesitate to write or call my office at (901) 528-5924. I'd be very happy to help you as much as I can with this proposal.

Sincerely,

A handwritten signature in cursive script, appearing to read 'Osama Gaber'.

A. Osama Gaber, M.D.

AOG:cr

enclosure: copy of Mrs. Kent's letter and survey questions

ANSWER SHEET/REFERENCE GUIDE

THIS SURVEY IS INTENDED TO DETERMINE THE ATTITUDES OF MEDICAL PROFESSIONALS TOWARDS TRANSPLANTATION AND ORGAN DONATION. ALL INDIVIDUAL SURVEY RESULTS WILL BE KEPT STRICTLY CONFIDENTIAL.

PLEASE ANSWER ALL QUESTIONS. THANK YOU.

HOSPITAL NAME: \_\_\_\_\_  
CITY STATE

CHECK CATEGORY: PHYSICIAN \_\_\_\_\_, SURGEON \_\_\_\_\_, NURSE \_\_\_\_\_, ADMINISTRATOR \_\_\_\_\_,  
OTHER (SPECIFY) \_\_\_\_\_

IF NURSE, PLEASE INDICATE HOSPITAL UNIT IN WHICH YOU WORK: \_\_\_\_\_

AREA OF SPECIALTY: \_\_\_\_\_

RACE: \_\_\_\_\_, MALE/FEMALE, RELIGION: \_\_\_\_\_, COUNTRY WHERE YOU TRAINED: \_\_\_\_\_

Place an "X" in the appropriate space below each of the statements below:

- Organ transplantation is an effective means of treatment for patients with end-stage organ disease. \* 7. All states have laws which permit the donation of organs for transplantation.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_ Yes X, No \_\_\_\_\_, Not Sure \_\_\_\_\_
- Heart transplantation is an effective means of treatment for selected patients with fatal heart disease. \* 8. It is legal for a live individual to sell one of his kidneys.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_ Yes \_\_\_\_\_, No X, Not Sure \_\_\_\_\_
- Liver transplantation is an effective means of treatment for selected patients with fatal liver disease. 9. Organ donors should be able to designate the race or religion of the recipient.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_ Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
- Kidney transplantation offers many advantages over dialysis treatment. \* 10. The family of a deceased patient who donates organs will receive a payment for the donation.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_ Yes \_\_\_\_\_, No X, Not Sure \_\_\_\_\_
- Only hearts, livers and kidneys can be transplanted at this time. \* 11. There are now laws which require hospitals to request organ donation from the families of all suitable deceased patients.  
Yes \_\_\_\_\_, No X, Not Sure \_\_\_\_\_ Yes X, No \_\_\_\_\_, Not Sure \_\_\_\_\_
- It is morally wrong to remove organs from one body and transplant them into another. \* 12. Most religions prohibit organ donation.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_ Yes \_\_\_\_\_, No X, Not Sure \_\_\_\_\_

Denotes questions for which there are absolute correct answers.

3. When a patient is considered a potential organ donor, the hospital staff view him only as a donor and not as a patient.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
4. The widespread use of organs for transplantation will lead to a decrease in the quality of care for critically ill patients.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
5. Removal of organs for transplantation is an unnecessary mutilation of the body of the deceased patient.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
6. Requesting organ donation puts an unfair strain on the families of deceased patients.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
7. Families of deceased patients will be offended if asked for organ donation.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
8. Organ donation leaves the hospital and staff open for lawsuits.  
Yes \_\_\_\_\_, No , Not Sure \_\_\_\_\_
9. Organs, such as the heart, liver, or kidneys, can be recovered after the donor's heart has stopped beating.  
Yes \_\_\_\_\_, No , Not Sure \_\_\_\_\_
10. Organ donors are patients who have suffered brain death, and are being maintained on respirators.  
Yes , No \_\_\_\_\_, Not Sure \_\_\_\_\_
11. A brain dead patient is not really dead until his heart and lungs stop.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
12. Turning of the respirator on a brain dead patient is mercy-killing.  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_

- \* 23. There are laws that recognize brain<sup>st<sup>at</sup></sup> death as legal criteria for a diagnosis of death.  
Yes , No \_\_\_\_\_, Not Sure \_\_\_\_\_
- \* 24. There are well established procedures for determining brain death.  
Yes , No \_\_\_\_\_, Not Sure \_\_\_\_\_
- \* 25. The organ donor is declared dead before the organs are removed and the respirator is turned off.  
Yes , No \_\_\_\_\_, Not Sure \_\_\_\_\_
- \* 26. The <sup>doctor</sup> physician who certifies the death of the organ donor can be involved in the removal or transplanting of the organs.  
Yes \_\_\_\_\_, No , Not Sure \_\_\_\_\_
27. Do you personally intend to leave your organs for transplantation?  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
28. Have you signed an organ donor card?  
Yes \_\_\_\_\_, No \_\_\_\_\_
29. Would you donate the organs of a deceased member of your family?  
Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_
30. Have you ever cared for an organ donor?  
Yes \_\_\_\_\_, No \_\_\_\_\_
31. Have you ever approached a family for consent for organ donation?  
Yes \_\_\_\_\_, No \_\_\_\_\_
32. Would you approach a family for consent for organ donation?  
Yes , No \_\_\_\_\_, Not Sure \_\_\_\_\_

The following set of questions is intended to survey your understanding of the current status of transplantation and organ donation. Again, please answer all questions.

FOR EACH OF THE QUESTIONS, 33., 34., and 35., PLEASE PLACE AN "X" IN THE APPROPRIATE SPACE IN EACH OF THE COLUMNS UNDER THE HEADINGS "KIDNEY," "HEART," AND "LIVER." FOR THE REMAINING QUESTIONS, PLEASE PLACE AN "X" IN THE APPROPRIATE SPACE BELOW THE QUESTION OR AS OTHERWISE INDICATED.

33. The number of transplants performed in The United States during 1986 was:

A. Kidney	B. Heart	C. Liver
1700 - 1900	300 - 400	500 - 600
(1) 2,000-4,000 _____	(1) 100 - 400 _____	(1) 100 - 400 _____
(2) 4,000-6,000 _____	(2) 400 - 800 _____	(2) 400 - 800 _____
(3) 6,000-8,000 _____	(3) 800-1,200 _____	(3) 800-1,200 <u>X</u>
(4) 8,000-10,000 <u>X</u>	(4) 1,200-1,600 <u>X</u>	(4) 1,200-1,600 _____

34. The one-year success rate of transplants is: *long as heart/lung 36 Cornea 2000 - 3000*

A. Kidney	B. Heart	C. Liver
(1) 20 - 40% _____	(1) 20 - 40% _____	(1) 20 - 40% _____
(2) 40 - 60% _____	(2) 40 - 60% _____	(2) 40 - 60% _____
(3) 60 - 80% _____	(3) 60 - 80% _____	(3) 60 - 80% <u>X</u>
(4) 80 - 100% <u>X</u>	(4) 80 - 100% <u>X</u>	(4) 80 - 100% _____

The number of patients awaiting a transplant in the U.S. is currently:

A. Kidney	B. Heart	C. Liver
(1) 2,000-4,000 _____	(1) 100 - 300 _____	(1) 100 - 300 _____
(2) 4,000-6,000 _____	(2) 300 - 500 _____	(2) 300 - 500 _____
(3) 6,000-8,000 _____	(3) 500 - 1,000 _____	(3) 500 - 1,000 <u>X</u>
(4) 8,000-12,000 <u>X</u>	(4) 1,000-2,000 <u>X</u>	(4) 1,000-2,000 _____

36. When was the last time you attended an inservice program conducted by the organ procurement agency at this hospital concerning organ donation?

36. Less than 6 months ago \_\_\_\_\_, 6 - 12 months ago \_\_\_\_\_, 1 - 2 years ago \_\_\_\_\_, Greater than 2 years ago \_\_\_\_\_, Never \_\_\_\_\_.

37. How frequently are terminal or deceased patients evaluated for organ and/or tissue donation in your unit at this hospital?

37. Always \_\_\_\_\_, Most of the time \_\_\_\_\_, Sometimes \_\_\_\_\_, Rarely \_\_\_\_\_, Never \_\_\_\_\_

38. Does your hospital have written protocols for organ recovery? (If your answer is "No" or "Not Sure", you may terminate the survey at this point).

38. Yes X, No \_\_\_\_\_, Not Sure \_\_\_\_\_.

39. Do you believe these protocols provide adequate guidelines for the donor and the hospital staff? *guidance (donor + hospital)*

39. Yes \_\_\_\_\_, No \_\_\_\_\_, Not Sure \_\_\_\_\_

40. Please write the name of the organ procurement agency specified in your hospital protocol as the organization to contact to refer a potential organ donor. *medical + nursing*  
 40. The Mid-South Transplant Foundation, Memphis. (901) 528-5923.

According to the hospital protocol, the following patient conditions absolutely rule out organ donation. (Please mark an "X" by all which apply).

- to rule out organ donation*
- |                                |  |
|--------------------------------|--|
| A. Age 50+ _____               | F. Prolonged use of high dose vasopressors _____ |
| B. AIDS <u>X</u>               | G. Greater than 48 hours on a respirator _____   |
| C. Septicemia <u>X</u>         | H. Bacterial Meningitis _____                    |
| D. Type II Diabetes _____      | I. Elevated serum creatinine _____               |
| E. Prolonged hypotension _____ | J. M.E. or coroner's cases _____                 |

2. According to the hospital policy, a terminal patient may be evaluated as a candidate for organ donation by the criteria listed in the hospital protocol only if the attending physician writes an order for it.  
Yes \_\_\_\_\_, No X, Not Sure \_\_\_\_\_
3. According to the hospital policy, permission to contact the organ procurement agency for a medical evaluation must be first obtained from the patient's next-of-kin. Yes \_\_\_\_\_, No X, Not Sure \_\_\_\_\_
4. According to the hospital policy, the approach to the patient's family to obtain permission for organ donation can be made only by the attending physician.  
Yes \_\_\_\_\_, No X, Not Sure \_\_\_\_\_

5. Please provide any comments or criticisms you have concerning the current approach to post-mortem organ donation. \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

THANK YOU FOR PARTICIPATING IN THIS SURVEY. YOUR ANSWERS WILL PROVE OF IMMENSE VALUE IN ACHIEVING AN UNDERSTANDING OF MEDICAL PROFESSIONALS' ATTITUDES TOWARD AND UNDERSTANDING OF TRANSPLANTATION AND ORGAN DONATION. THIS UNDERSTANDING WILL HELP US TO BETTER SERVE YOUR INSTITUTION AND PATIENTS THROUGHOUT OUR COUNTRY AWAITING A BETTER LIFE THROUGH ORGAN TRANSPLANTATION.

PLEASE RETURN THIS COMPLETED SURVEY FORM TO YOUR UNIT SUPERVISOR. THANK YOU.

**Appendix 8: The information letter sent with the questionnaires.**



HEALTH STUDIES RESEARCH DIVISION  
Fron Heulog  
Ffordd Ffriddoedd  
BANGOR  
Gwynedd LL57 2EF

Tel: 01248 354036 Ext 234  
Fax: 01248 355830

Our Ref: bk/ods



Bridie Kent, Postgraduate Research Nurse

Dear

I am carrying out a research project in hospitals in North Wales and Leicester which will increase our understanding of the role of the nurse and other issues related to donation and transplantation and would like your help in this matter. Research suggests that nurses play a very important role in the donation process and I feel it is necessary to gain a complete picture of nurses' feelings and reactions to this process if we are to meet the needs of those caring for potential donors and those being cared for.

I would be very grateful if you would spare a little of your time to participate in this stage of the research. Please complete the Organ Donation Attitude Scale first and then the Organ Donation and Transplantation questionnaire. These questionnaires address both attitudes and knowledge and are designed to further our understanding of this important area.

I have organised the questions and responses in such a way that they are easy to fill in and all responses will be kept completely confidential. Names are not need but if you would like to participate in individual interviews which are the next phase of the study, then please give your name and telephone number in the spaces provided at the end of the second questionnaire.

I appreciate that there are many demands on your time, but I would be very grateful if you could spare about half an hour to complete the questionnaires and return both of them in the envelope provided (no stamp is needed).

Thank you very much for your help.

Yours sincerely

Bridie Kent

## **Appendix 9: The interview schedule**

## **Semi - structured Interview Schedule**

### **Identification of potential tissue/organ donors**

#### Introduction

- Information about me: who I am; what I do
- Purpose of the research and purpose of the interview
- Why/How the interviewee was selected.
  
- Confidentiality, note-taking and tape-recording

Before we go any further I'd like to ask your permission for the use of a tape recorder to record our conversation today. I may also take some notes during the course of the interview. A number of nurses are to be interviewed and any information given will be kept confidential; your identity will not be revealed at any time. Once all the data has been analysed any identifying information on the tape will be erased. If you would prefer, I will return the tape to you once the analysis has been completed.

(Turn on the tape-recorder and ask if it OK to tape the interview. Wait for a decision, rewind the tape and check that the recording is satisfactory commencing with the interview)

Several months ago you completed a questionnaire about organ donation - I'd just like to check whether the following information you then is still accurate:(interviewer to read back their original details)

1. What is your area of work?
2. What is your current grade?
3. Have you been promoted ?
4. Have you gained any further qualifications since you completed the questionnaire?

#### **Interview Questions**

##### **A) Experiences of the donation process -**

I'd like to begin by asking a few questions about any experiences that you might have had of organ or tissue donation.

1. You are working in medical/surgical/ITU/CCU/A&E area at the moment.
2. How long have you worked there?
3. In general, what sort of conditions are your patients admitted with?
4. Have you worked in any other area of nursing during your nursing career?
5. During this time, have you had any experience of organ or tissue donation? If so - please try to explain what it was?

6. . Have you ever helped to care for someone who was to be a potential donor? (If so)- could you tell me what your role was when caring for this patient?
7. . What are the positive aspects, the good things, about donation? Probe
8. . Can you think of anything that has altered your views on donation in any way? If so - please try to tell me about it. Probe positive and negative
9. . Are there any aspects of donation that worry you? Probe

## **B) Knowledge**

1. How would you describe your level of knowledge of what happens in the donation process? - Probe : origin of knowledge:- experience; media; word of mouth?
2. Have you ever attended a study day or session that focused on organ donation? (If yes) Probe:
  - how useful did you find it?
  - Can you think of anything that you would have found useful that wasn't included in the session?
  - Who organised or ran the session?
  - How did you find out about the session?
 If no:
  - how useful do you think an information day would be to you?
  - Who do you think would be the most appropriate organisation to run the session: hospital, school of nursing; other?
  - Have there been any study days on organ donation that you have actively wanted to go to but couldn't?
3. Most of the education initiatives that have taken place in this area seem to have been aimed at intensive care unit staff - what are your feelings about this balance of provision? Probe to see if the interviewee sees organ donation in a wider sense ie. As tissue donation as well.
4. Do you think that it would be appropriate for donation education to be directed at ward-based staff? Probe

## **C. The Donation Process**

1. In the questionnaire you suggested that the best person to initiate discussions about donation, is:.....  
Probe:  
Can you tell me more about your reasons for saying this? (Try to uncover why this person is the best)

2. You also mentioned in the questionnaire that you personally would/would not feel able to approach families to discuss donation. Probe: Why did you say this?

Listen for factors that may be perceived motivators/barriers.

3a. What do you see as the biggest barriers to talking about possible donation with families? try to identify if any of the following, which have been suggested as barriers in previous research, are perceived as barriers here: peer pressure; manager pressure; attitudes of medical staff, fear of increasing distress; fear of disfigurement; insufficient knowledge to deal with questions.

Can you think of any circumstances of death where

3b. This set of barriers would not affect your willingness to discuss donation with families?

3c. Additional barriers might affect your willingness to discuss donation.

(Interviewer is trying to discover if there are any situations perceived as more difficult than others)

Can you suggest any ways you might overcome these barriers?

4. What do you see as the extent of nursing involvement, in these aspects of organ donation which involve discussions with families? Probe-

5. If a family in these situations asked you for information about donation, how would you deal with this? Probe

- Would you be able to say if the patient would be a potential donor (donor criteria)?
- Where or to whom, would you turn to gather the information? Probe ( try to uncover relationship with medical staff)

## **D) Increasing donor awareness**

We've talked about your views on donation and explored issues associated with the discussion phase of the donation process. Now I would like to ask you to think about the future; specifically about meeting patients' needs in relation to donation wishes.

1. What suggestions can you make that would improve the documentation of patients' wishes in relation to possible donation of organs or tissue after death? Probe - admission sheet, patient's notes, PAS system?
2. If these changes in documentation were introduced into the clinical area where you work, what would be the reaction of the medical and nursing staff? Probe - positive and negative.?

3. What steps would have to be taken to prepare staff for these changes in documentation? Probe - specific changes e.g. Information to staff, training, role changes staff meeting discussions.
4. In what other ways can nurses contribute towards resolving the tissue and organ donor shortfall?
5. What problems can you foresee for nurses being enabled to make these contributions
6. How can collaboration between nurses and doctors be improved? Probe - communications, joint documentation, changes to role demarcation.

Before we finish this interview, are there any questions or additional comments for me?

Thankyou for giving me this time and sharing with me your views and experiences. It may be necessary for me to contact you again to clarify any points raised - would ~~this~~ be acceptable to you?

## **Appendix 10: The students' questionnaire**

## **Organ Donation and Transplantation Beliefs and Knowledge Questionnaire**

This questionnaire is part of a research project exploring nurses' beliefs and knowledge about issues related to organ and tissue donation. Previous research suggests that nurses play a very important role in the donation of organs and tissue after death. This research will add to the existing knowledge and help to meet the needs of the health professionals who care for potential organ donors as well as the needs of those being cared for.

This part of the study will evaluate student nurses' attitudes and knowledge to see if socialisation into nursing influences our feelings about organ donation and transplantation.

I have organised the questions and responses in such a way that they are easy to complete. Please indicate your first thoughts and I would appreciate it if you did not discuss the questions with your colleagues until you have completed the questionnaire.

All responses will be kept completely confidential and you do not have to give your name if you don't want to. However I would like you to indicate your group number (eg. 1/92) in the space below.

Please put the completed form in the envelope provided and leave it in the box marked "Bridie" at reception on the 1st floor.

Many thanks for your time and help. In return for your assistance, I will ensure that you are kept up-to-date with the progress of the research.

Yours sincerely

Bridie Kent

.....

Name (optional):

Group:



1. Please estimate for each category, the number of patients who are awaiting a transplant in the UK by placing a circle around the appropriate figures.

a) Kidney	2000 - 3000	3000 - 4000	4000 - 5000	
b) Heart	50 - 100	100 - 200	200 - 300	300 - 400
c) Liver	50 - 100	100 - 200	200 - 300	300 - 400
d) Lung	50 - 100	100 - 200	200 - 300	300 - 400
e) Heart/lung	50 - 100	100 - 200	200 - 300	300 - 400
f) Cornea	<100	100 - 500	500 - 1000	1000 - 2000 - >2000

2. Heart transplantation is an effective means of treatment for certain people with terminal heart disease.

strongly agree    agree    undecided    disagree    strongly disagree

3. Liver transplantation is an effective means of treatment for certain people with terminal liver disease.

strongly agree    agree    undecided    disagree    strongly disagree

4. In the long term, is kidney transplantation more expensive than dialysis treatment?

Yes    No    Not sure

5. Organs, such as the heart, lungs or liver can be removed for transplantation purposes after the donor's heart has stopped beating.

always    usually    sometimes    never

6. In the UK, the family of a deceased patient who donates organs will receive payment for the donation.

Yes    No    Not sure

7. A brain -stem dead patient is not dead until the heart stops.

Yes    No    Not sure

8. There are well established procedures for determining brain stem death.

Yes    No    Not sure

9. The organ donor is declared dead before the organs are removed and the ventilator is switched off.

always    usually    sometimes    never

10. In the UK, health professionals consult the deceased person's relatives about donation even if a donor card had been signed.

always    usually    sometimes    never

11. The doctor who diagnoses and certifies the death of the organ donor can be involved in the removal or transplantation of the organs.

always usually sometimes never

12. In the UK, it is legal for a live individual to sell one of his/her kidneys.

Yes No Not sure

13. In the UK, health professionals must, by law, make a request for organ donation to families of all suitable deceased patients.

Yes No Not sure

14. Most religions prohibit organ donation.

Yes No Not sure

15. There is an upper age limit for the donation of most organs and tissues. Please indicate the upper age limits of donors of the following :-

Heart	<input type="text"/>
Kidney	<input type="text"/>
Corneas	<input type="text"/>
Heart Valves	<input type="text"/>
Liver	<input type="text"/>
Bone	<input type="text"/>

16. Tissues, such as heart valves and corneas, can be retrieved from a body after the heart has stopped beating.

Yes No Not sure

17. The kidney can be retrieved from a body after the heart has stopped beating.

Yes No Not sure

18. Have you read any information about the new NHS Organ Donor Register?

Yes No

If yes, please state the source of the information -

**On the next pages are statements of beliefs about organ donation. Please read each one and decide the extent to which *you* agree or disagree. Indicate the strength of your feelings by selecting one of the following for each statement:**

Agree strongly  
Agree  
Agree slightly  
Disagree slightly  
Disagree  
Disagree strongly

There are no right or wrong answers so please indicate how *you* feel about each statement.

1. By agreeing to donate organs at death, one sets a good example for others to follow.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
2. Deciding to donate one's organs at death adds extra meaning to life.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
3. Donating a body part would enable that part of myself to remain alive after my death.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
4. Organ donation leaves the body disfigured.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
5. Organ donation interferes with an open-casket funeral service.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
6. Transplanting organs is against God's will.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
7. Preparing to become an organ donor brings to mind unpleasant thoughts of my own death.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
8. A person will be less likely to receive adequate medical care after signing a donor card.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
9. Hearing about people whose lives were saved after the receipt of an organ makes me think about the importance of donating my organs after death.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
10. Organ donation should not be considered because the body is sacred and has religious meaning after death.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
11. Donating organs at death is a way of putting some parts of the body to beneficial use.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
12. The surest way to bring about my own death is to make plans for it, like signing a donor card.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
13. The person who offers a part of his or her body for transplantation is making a really precious gift.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
14. By agreeing to donate my organs after death, I am giving some people hope for survival.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly
15. It is unnatural to prolong life with body replacements.  
strongly agree    agree    agree slightly    disagree slightly    disagree    disagree strongly

16. When I die I want the whole of my body to die with me.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
17. Life is much too valuable to be cut short by a bad heart or kidneys, especially when organ donation can help to solve the problem.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
18. By signing a donor card, doctors might do something to me before I am really dead.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
19. A person with someone else's heart, eyes, kidney etc. is not the same person.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
20. By donating a body part after my death, I could keep another person living.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
21. The thought of my body being cut up or taken apart after I'm gone makes me feel uneasy.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
22. By donating an organ at death, one can offer someone a better chance of being cured.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
23. When I die I want to be buried whole and with all my original parts.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly
24. It is a shame to deny a person the organs he or she needs to keep the body functioning.  
 strongly agree      agree      agree slightly      disagree slightly      disagree      disagree strongly

25. How useful or effective do you think is the transplantation of the following organs?  
 (Circle the appropriate answer)

- |    |               |                |           |         |
|----|---------------|----------------|-----------|---------|
| a) | Heart         | Very effective | Effective | Useless |
| b) | Lungs         | Very effective | Effective | Useless |
| c) | Eyes(corneas) | Very effective | Effective | Useless |
| d) | Bone-marrow   | Very effective | Effective | Useless |
| e) | Liver         | Very effective | Effective | Useless |
| f) | Bone          | Very effective | Effective | Useless |
| g) | Pancreas      | Very effective | Effective | Useless |
| h) | Heart valves  | Very effective | Effective | Useless |
| i) | Kidney        | Very effective | Effective | Useless |
| j) | Skin          | Very effective | Effective | Useless |

26. Are there any organs which you would never consider donating? (please specify)

If so, please give reasons ?

27. Would you accept into your body a transplanted human organ if you needed one to survive?  
Yes No Maybe

28. Please circle the appropriate response that you would make if you were asked to indicate your willingness to donate organs after death by signing a donor card -

I do not want to donate any of my parts after I die and I do not want to sign a donor card.

I am undecided about signing a donor card; I don't think I would like to donate my organs.

I am undecided about signing a donor card but I think that I would want to donate my organs.

I want to donate my organs and I would like to sign a donor card.

I have already signed a donor card.

29. At present, the UK system for donating organs after death is called 'opting - in' ; Would you support a change to this system? Please indicate your decision below.

Opting - Out Yes No Don't know

Please give reasons for your decision.

Required Request Yes No Don't know

Please give reasons for your decision.

Any other suggestions?

Many thanks for sharing your feelings and thoughts with me. I would like to stress again that all information given will remain confidential. Your responses will be of great value in increasing our understanding of donation issues and in improving the service given to patients, their relatives and to the nurses caring for them.

Yours sincerely

Bridie Kent

## **Appendix 11: Information related to deaths in hospital**



THE  
LEICESTER ROYAL INFIRMARY  
NHS TRUST

ACCIDENT &  
EMERGENCY  
DEPARTMENT

HEAD OF SERVICE

Mr G Bodiwala  
Tel: 0116 258 5274

CONSULTANTS

Mr D Quinton  
Tel: 0116 258 5646

Mr P A Evans  
Tel: 0116 258 6320

Our ref: RHB/EJ

13th January 1997

Mrs. B.C. Kent  
Lecturer  
School of Nursing & Midwifery Studies  
Faculty of Health  
University of Wales  
Bangor  
LL57 2EF

Dear Bridie

Thank you for your letter of 7th December 1996, asking for information on the number of adult deaths (18yrs+) in this department.

For the period 1 Jan 96 - 31 Dec 96, there were a total of 171 patients who died in the department and a total of 109 who were dead on arrival at the department.

Our total new patient attendances for the same period was 105737 patients.

For information on the medical and surgical directorate and CCU & ITU deaths, you need to contact the following people.

Janet Williamson, Business Manager, Medical Directorate  
John O'Connor, Business Manager, Surgical Directorate  
David Edgar, Business Manager, Critical Care Unit

I hope this information is of use to you in your research project.

Yours sincerely

*H. Edgar*

ADDRESS

Leicester  
LE1 5WW

**NUMBERS OF ADULT ADMISSIONS and DEATHS (SURGICAL DIRECTORATE)  
FOR THE YEAR ENDING DECEMBER 1996**

SPECIALTY	ALL ADMISSIONS		ADULT ADMISSIONS		ADULT DEATHS	
	Male	Female	Male	Female	Male	Female
General Surgery	3668	4299	3576	4166	73	83
ENT	3297	4031	1992	2407	8	4
Ophthalmology	2434	1850	2319	1693	0	1
Oral Surgery	612	522	512	447	0	0
Plastic Surgery	1882	1751	1619	1376	5	4
<b>TOTAL</b>	<b>11893</b>	<b>12453</b>	<b>10018</b>	<b>10089</b>	<b>86</b>	<b>92</b>



**Appendix 12: Summary of student nurses' knowledge responses.**

Appendix 12: Student cohorts' correct answers, showing stage of training

Question No. & Details	Stage of Training		
	Beginning (n = 47)	Middle (n = 94)	End (n = 11)
1a: Number of people waiting for a Kidney transplant in the UK?	51% (n = 24)	53% (n = 50)	54% (n = 6)
1b: Number of people waiting for a Heart transplant in the UK?	25% (n = 12)	37% (n = 35)	36% (n = 4)
1c: Number of people waiting for a Liver transplant in the UK?	29% (n = 14)	25% (n = 24)	36% (n = 4)
1d: Number of people waiting for a Lung Transplant in the UK?	29% (n = 14)	32% (n = 30)	18% (n = 2)
1e: Number of people waiting for a Heart/Lung transplant in the UK?	29% (n = 14)	24% (n = 23)	9% (n = 1)
1f: Number of people waiting for a Corneal transplant in the UK?	40% (n = 19)	47% (n = 44)	54% (n = 6)
4: In the long term, is kidney transplantation more expensive than dialysis?	79% (n = 37)	81% (n = 76)	91% (n = 10)
5: Organs, such as the heart, lung or liver, can be removed for transplantation after the donor's heart has stopped beating?	25% (n = 12)	28% (n = 26)	91% (n = 10) *
7: A brain stem dead patient is not dead until the heart stops?	53% (n = 25)	45% (n = 42)	54% (n = 6)
8: There are well established procedures for determining brain stem death?	72% (n = 34)	79% (n = 74)	91% (n = 10)
9: The organ donor is declared dead before the organs are removed and the ventilator is switched off?	57% (n = 27)	55% (n = 52)	82% (n = 9) *
10: In the UK, do health professionals consult the deceased's relatives about donation even when a donor card has been signed?	59% (n = 28)	66% (n = 62)	82% (n = 9)
11: Can the doctor who diagnoses and certifies the death or the organ donor be involved in the removal or transplantation of the organs?	30% (n = 14)	31% (n = 29)	45% (n = 5)
12: In the UK is it legal for a person to sell a kidney?	79% (n = 37)	83% (n = 78)	91% (n = 10)
13: In the UK, must health professionals, by law make a request for organ			

Question No. & Details	Stage of Training		
	Beginning (n = 47)	Middle (n = 94)	End (n = 11)
donation to relatives of all suitable deceased patients?	23% (n = 11)	36% (n = 34)	9% (n = 1) *
14: Do most religions prohibit organ donation?	45% (n = 21)	48% (n = 45)	54% (n = 6)
15: What is the upper age limit for potential donors of :			
Heart ?	32% (n = 15)	36% (n = 34)	45% (n = 5)
Kidney?	21% (n = 10)	23% (n = 22)	64% (n = 7)
Corneas?	8% (n = 4)	7% (n = 7)	18% (n = 2)
Heart-valves?	19% (n = 9)	24% (n = 23)	64% (n = 7)
Liver?	42% (n = 20)	46% (n = 43)	64% (n = 7)
Bone?	15% (n = 7)	18% (n = 17)	27% (n = 3)
16: Can tissue for transplantation be retrieved from a body after the heart has stopped beating?	55% (n = 26)	67% (n = 63)	64% (n = 7)
17: Can kidneys be retrieved from a body after the heart has stopped beating and still be used for transplantation?	40% (n = 19)	48% (n = 48)	9% (n = 1)

## **Appendix 13: Enquiring about donation intentions: pilot study**

### **A pilot scheme for developing confidence in donation discussion ability.**

A pilot scheme, intended to assess a method of developing nurses' confidence in discussing donation intentions with patients, was instigated, in December 1997, in one acute hospital in North Wales. The impetus for the project came from members of the public, who made official complaints about the failure of health professionals to enquire about donation intentions upon the deaths of their relatives. These complaints, together with the findings of the present research, led to an examination of initiatives that could be implemented to encourage discussion behaviour.

In conjunction with the regional transplant co-ordinator, a form was developed that guided the nurse to enquire, during the in-patient admission process, about a patient's donation intentions. To minimise the possibility of causing distress, a fear expressed in Studies One and Two, the inquiry was worded such that the patient was asked if they were aware of the NHS organ and tissue donation register. Permission was sought, from the Director of Nursing, and the Director of Medicine, to allow clinical areas to be used to assess the effectiveness of this initiative, and was duly given.

The pilot period lasted for 3 months, and was undertaken in a general medical ward, and an A&E department. Thorough briefings were given to nursing staff prior to the pilot commencing, thereby providing opportunities for questions. These briefing also provided an indication of the level of anxiety that the planned behaviour provoked among the nursing staff. A supply of information leaflets was made available, which would give further details about the donor register, and organ donation to patients, or relatives, if required. To address the concern identified by respondents in Studies One and Two, that they wanted some

support during this aspect of the donation process, an advisor was made available at all times.

The completed inquiry forms were copied, and the original placed in the nursing notes. The copy was collected by the transplant co-ordinator, or myself, and the information collated. There was a high level of enthusiasm for the initiative early on in the pilot period. However, this waned, in both clinical areas. With hindsight, the timing of the pilot was inappropriate, since it coincided with the busiest period of the hospital's year: the winter months. The nurses reported that they forgot to ask about donation intentions when the ward or department was busy, and when time was in short supply.

The nurses indicated, informally, that they had been pleasantly surprised by the reactions of the patients and their relatives. No strong adverse reactions were observed by the staff, and generally, the responses were similar to those evoked by other inquiries, such as religious affiliation. These limited findings find support from a more extensive study, performed by Justin and Johnson (1989) in the USA.

The pilot scheme identified two key problems that will require attention before the project is extended hospital-wide. Firstly, the prompt, for the inquiry, needs to be incorporated into the assessment documents, used by nurses, to record patients' personal details, and base-line data to identify needs or problems. The use of a separate piece of paper appeared to discourage inquiries, by adding an extra time burden onto the nurses. They had to remember that the inquiry had to be made, and obtain the additional form. The significance of this, as a determinant of behaviour, is questionable. Conscious thought has to be employed for new practices, as part of normal socialisation, until these become internalised and competency is achieved (Benner, 1984). Therefore, with perseverance, learning new practices, through experiential learning, which helps the confidence-boosting process, is achievable.

The second problem that emerged from the pilot study focused on the wording of the inquiry. The responses to a question that indirectly elicits donation intention information may be of limited value. Knowledge of awareness of the donor register does not provide information about a person's donation intentions, unless the initial inquiry is used as a stem question, prior to future probing. This type of questioning takes time, and when the ward is busy, and time is short, it provides the nurse with another excuse to avoid the inquiry. Disguising the real question by asking another associated, but less direct, question may be counterproductive. If patients have genuine doubts about the reason for such an inquiry, indirect questioning may provide further justification for this anxiety. He or she may feel that the nurse is hiding the real reason for asking. Therefore a trial of direct questioning is indicated before the programme is extended.

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