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A psychosocial approach to illness cognition, emotional coping responses and lay referral: an exploratory mixed and multi-methods design within early diagnostic cancer research

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**School of Health Sciences
Bangor University**

**A psychosocial approach to illness cognition, emotional coping responses
and lay referral: an exploratory mixed and multi-methods design within
early diagnostic cancer research**

Emma Campbell

Submitted in fulfilment of the requirements for the degree of Doctor of Philosophy

Bangor University September 2021

'Yr wyf drwy hyn yn datgan mai canlyniad fy ymchwil fy hun yw'r thesis hwn, ac eithrio lle nodir yn wahanol. Caiff ffynonellau eraill eu cydnabod gan droednodiadau yn rhoi cyfeiriadau eglur. Nid yw sylwedd y gwaith hwn wedi cael ei dderbyn o'r blaen ar gyfer unrhyw radd, ac nid yw'n cael ei gyflwyno ar yr un pryd mewn ymgeisiaeth am unrhyw radd oni bai ei fod, fel y cytunwyd gan y Brifysgol, am gymwysterau deul cymeradwy.'

Rwy'n cadarnhau fy mod yn cyflwyno'r gwaith gyda chytundeb fy Ngrichwyliwr (Goruchwylwyr)'

'I hereby declare that this thesis is the results of my own investigations, except where otherwise stated. All other sources are acknowledged by bibliographic references. This work has not previously been accepted in substance for any degree and is not being concurrently submitted in candidature for any degree unless, as agreed by the University, for approved dual awards.'

I confirm that I am submitting the work with the agreement of my Supervisor(s)'

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Summary

The time frame in which people recognise a bodily change as a potentially cancerous illness symptom and seek professional healthcare advice has been a topic of research from the 1970s. Exploring and understanding these processes are important especially when considering the earlier diagnosis of cancer. Previous research has examined the role of several factors which may influence these processes including differing social, psychological, and psychosocial factors. However, little is known about these factors in specific reference to bodily changes. Therefore, the current research aimed to investigate the role of symptom perception/ interpretation, emotional coping responses, and lay referral in the context of the time frame between symptom recognition and professional healthcare help-seeking behaviour. An exploratory approach was taken, with the presentation of the historical literature, and a scoping review which mapped the evolution of the theoretical conceptualisation of lay referral and demonstrated the psychosocial nature of lay referral including how professional healthcare help-seeking is potentially influenced through this process. A cross-sectional, inductive, idiographic Interpretative Phenomenological Analysis (IPA) study was conducted to explore the experiential and lived experience of bodily changes, symptom recognition, emotional coping responses, and lay referral. The findings highlighted the significant influence that people's previous interpersonal experiences with their family and close relationships had on how they make sense of any ambiguous, fleeting bodily changes, emotional regulation, relational-affect, lay referral, and help-seeking behaviour. An explanatory integrated theoretical framework was proposed to aid the interpretation of the findings. This framework encompassed The Common Sense Model, Interpersonal Cognition, and Adult Attachment Theory. A contemporary concept of lay referral was also discussed in connection to the study findings. The results of the IPA study informed the design of the mixed and multi-methods study. Next, a mixed and multi-methods study took an integrated concurrent triangulation pluralistic comparison design using an online survey, the story completion task, photo elicitation, and template analysis. This study examined the influence of illness perceptions, personal factors, and adult attachment style on people's thoughts, emotions, and coping responses; whilst also exploring how adult attachment style influences people's narratives concerning lay referral and consultation behaviour in the context of experiencing bodily changes during a world pandemic i.e. SARS-Cov2/ COVID19. The results supported previous literature in connection to the influence of a pre-existing health condition on illness perceptions and in finding gender differences in lay referral. However, it was through the triangulation of the abductive qualitative analysis and quantitative results that a more in-depth understanding arose. The results exemplified how all of the participants perceived a low to medium health threat with the majority engaging

with lay referral in response to their bodily changes and some gaining professional healthcare advice. However, participants' perceptions of the experiential aspects of lay referral and help-seeking during the pandemic presented certain similarities whilst also showing differences when compared across the different adult attachment styles. The thesis concludes with a general discussion of the different study findings and how these have contributed to current theoretical understanding of how the perception and interpretation of bodily changes influence emotional coping responses, presents a relational conceptualisation of lay referral, and highlights implications for cancer related policy, suggested interventions, and potential future directions of research.

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***“I won’t go to the doctors unless I’m dying”*: An interpretative phenomenological analysis of the perception and interpretation of bodily changes, emotional coping responses and lay referral**

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Chapter One

General Introduction

Introduction

The Early Diagnosis of Cancer and Cancer Incidence

The early diagnosis of cancer is paramount in order to increase survival, prognosis and to decrease people's emotional distress when they experience illness symptoms connected to psychological anxiety (Scott et al., 2013). In accordance with the World Health Organization (WHO, 2021), cancer is the second leading cause of death globally, accounting for approximately 10 million deaths in 2020. In 2020 the most commonly diagnosed cancers globally were breast cancer (2.26 million); lung cancer (2.21 million); colon and rectum (1.93 million); prostate (1.41 million); skin cancer (non-melanoma 1.2 million) and stomach (1.09 million cases). WHO has also reported that in 2020 alone 1.80 million people died from lung cancer; 935,000 deaths occurred due to colon and rectum cancer; 830,000 people died due to liver cancer, 769,000 from stomach and 685,000 people from breast cancer. It was estimated that 2.7 million people across Europe in 2020 would experience cancer; 1.3 million would die (OECD, 2020). In the United Kingdom alone, between 2015 and 2017, approximately 1,000 people were newly diagnosed with cancer each day and 367,000 new cases were reported each year (Cancer Research, 2021). Incidence rates in the United Kingdom are rated higher than two-thirds of Europe, ranked higher than 90% of the world and when all cancer diagnoses are combined, incidence rates are projected to increase by 2% in the UK by 2035 (742 cases per 100,000 people) (Cancer Research, 2021). These statistics reported by Cancer Research UK, exemplify the severity and devastating population-level consequences of cancer. This can be further exemplified by the Welsh Cancer Intelligence and Surveillance Unit (WCISU, 2018) report (which is the most up-to-date publication due to the COVID-19 pandemic). Here, the report indicates that in Wales alone between 2016 and 2017, there were 8,936 cancer related deaths (see Table 1.1 below).

Table 1.1*Mortality Rates in 2017 from Different Types of Cancer Amongst People in Wales*

| Cancer Type | Number of Deaths in Wales 2017 |
|----------------------|--------------------------------|
| Lung cancer | 1891 |
| Colorectal cancer | 921 |
| Breast cancer | 622 |
| Prostate cancer | 605 |
| Pancreas cancer | 505 |
| Oesophagus cancer | 436 |
| Liver cancer | 320 |
| Stomach cancer | 285 |
| Bladder cancer | 270 |
| Non-Hodgkin Lymphoma | 241 |

The Early Diagnosis of Cancer and UK Policy

Given the above it is clear why there is an important focus on the early diagnosis of cancer in the UK and across Europe; with the OECD (2020) indicating that over 40% of projected cancer incidence could be preventable and mortality reduced through earlier diagnosis (OECD, 2020). The early diagnosis of cancer has been the focus of national policy for some time, as demonstrated through the Department of Health (DOH, 2007) policy report which was called 'The Cancer Reform Strategy' that built upon previous policy such as The NHS Cancer Plan (NHS, 2000) that specifically encompassed an action plan with regards to the early diagnosis of cancer. The 2007 Cancer Reform Strategy highlighted that the late diagnosis of cancer had previously been a major factor contributing to poor cancer survival rates in the UK. This led to the development of several new National Awareness and Early Diagnosis initiatives to raise public awareness of cancer symptoms and to encourage people to seek help early (DOH, 2007).

The 'Be Clear on Cancer' (BCOC) campaign (2011) was one of these initiatives and has been piloted at a local level, then regionally, with the overall end aim being at a national level. Data evaluated in 2013 (amongst other results) following one of the BCOC campaigns, for example, saw an increase of 29% in people over the age of 50 years self-reporting symptoms related to the campaign. This focus upon the early diagnosis of cancer was also on the Welsh government agenda during this time and in June 2012, the 'Together for Health: Cancer Delivery Plan for the NHS to 2016' was launched. The 'Together for Health: Cancer Delivery Plan for the NHS to 2016' provided a framework of action across several different Welsh health boards and aimed to measure how successful the detection of cancer, treatment, and care was for people living in Wales.

The plan was reviewed in 2014 by the Welsh government and re-developed, which saw the publication of the 'Cancer Delivery Plan for Wales 2016-2020'. The overall report included several areas for development (i.e., increase in communication across primary and secondary care services); one of which was to increase public symptoms awareness. The report highlighted how some campaigns would focus upon 'alarm' symptoms for cancer although many symptoms may not be cancer specific and that there was a need for primary care training, assessment tools, and access to specialist services for advice. Here, the focus was not only upon classically known cancer symptoms but also the early diagnosis of cancer when people experience a variety of symptoms that may need monitoring, referral for further investigation, specialist advice, or signposting (National Institute for Health and Care Excellence [NICE], 2021). The importance of symptoms that may not be cancer specific or 'vague' symptoms such as unexplained weight loss, nausea, continued fatigue, abdominal pain, and 'not feeling yourself' is the specific focus of a six-month Cancer Research Wales campaign in South Wales launched in July 2021. The campaign aims to encourage adults to gain healthcare advice if symptoms proceed beyond three weeks (Cancer Research Wales, 2021). However, given that there are over 200 types of cancer that on occasion involve different symptoms or overlapping symptoms, this can not only influence when or how (or not) people gain professional healthcare advice but if or how the potential diagnosis of cancer takes place in primary care. The next section will now outline the NICE guidelines (2021) for 'Suspected Cancer: Recognition and Referral' which encompasses a section with regards to unexplained symptoms.

NICE Guidelines; Suspected Cancer, Recognition and Referral. The Welsh government 'Cancer Delivery Plan for Wales 2016-2020' is aligned with the updated NICE (2021) guidelines that offer a range of referral pathways for investigation following the recognition of potential cancer symptoms. For example, if people over the age of 40 experience two or more of the following unexplained symptoms: cough, fatigue, chest pain, weight loss, appetite loss, and/ or fatigue; they can be referred for an urgent chest X-ray based upon the recommendations organised by the site of cancer. However, the recommendations differ if the healthcare professional is uncertain whether a referral is required or if the person's symptoms meet the criteria for any further medical investigations. One aspect (amongst others) detailed in the guidelines is about 'safety netting'. Safety netting has been described in the NICE (2021) guidelines as a way in which to actively monitor people who experience symptoms across two domains. The first relates to timely review/ and post-investigation action. The second refers to active monitoring for those who are low risk (not, no risk) and managing this risk. Here, the focus is upon the healthcare professionals to review, take the appropriate action, or pass patients to another professional. Reviews are also recommended to be planned (patient-initiated) with the person, if the person experiences new symptoms, if the person continues to be concerned, or if the symptoms recur, persist, or become more severe. However, in accordance with Cancer Research UK (2020), not every GP practice has a safety netting protocol in place, although Macmillan Cancer Support (2021) has developed an e-learning course aimed at GPs. This has been designed to increase awareness, the quality of healthcare professionals' coding, and electronic methods of safety netting within clinical practice. Alternatively, Cancer Research UK (2020) has also created a summary checklist that contains three different areas of action associated with safety netting (communication with patients, actions for GPs, and actions for practices). The patient communication checklist created by Cancer Research UK (2020) builds on the NICE (2021) guidelines and offers several points for discussion during consultation associated with safety netting which are outlined below:

- The likely time course of current symptoms
- When to come back if symptoms do not resolve in the expected time course
- Specific warning/ red flag symptoms or changes to look out for

- Who should make a follow up appointment with the GP, if needed
- The reasons for tests or referrals
- Next steps. How to obtain results, the importance of attending appointments
- The importance of coming back if symptoms continue, even after a negative result.

However, the checklist does not offer guidance regarding patient communication when people do not fit referral criteria. Therefore, it is evident that not only classically well-known cancer symptoms are important with regards to current policy, campaigns, and clinical practice, but encouraging people to seek professional healthcare advice about 'vague', unexplained symptoms to increase the earlier diagnosis of cancer is vital. This is vital given the complexity of diagnosis, referral pathways, and how unexplained symptoms can also create delay when people enter into healthcare services by reference to referral and investigative diagnostic procedures, etc.

The Impact of the COVID-19 Pandemic. Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) is the coronavirus that causes Corona Virus Disease (COVID-19), a disease whereby most of those infected experience mild to moderate symptoms (i.e., a loss/ change of smell/ taste, high temperature, dry/ continuous cough, tiredness (WHO, 2021). Other less common symptoms are aches, pains, sore throat, diarrhoea, and headaches; whilst more serious symptoms include difficulties breathing, shortness of breath, chest pain, and chest pressure (WHO, 2021). These symptoms overlap with other common conditions and respiratory illnesses such as influenza (flu), although differences also exist regarding the spread, severity, incubation period, and how long people may be contagious (Centres for Disease Control and Prevention, 2021). WHO first declared the COVID-19 pandemic in December 2019 in China which then spread across the world (Liu et al., 2020). In accordance with WHO (2021), there have been 198,022,041 confirmed cases of COVID-19 and 4,223,460 deaths as recorded in August 2021 globally. In the United Kingdom from January 2020 to August 2021, there were 5,856,532 confirmed cases and 129,654 deaths (WHO, 2021).

The impact of the COVID-19 pandemic on cancer has been explored in recent research by Archer et al. (2021) as there has been evidence of an increase in

avoidable cancer related deaths during the pandemic. To examine this in more detail Archer et al. (2021) conducted a qualitative study that aimed to give insight into GPs' perspectives with regards to the impact of the COVID-19 pandemic in reference to the assessment of those who are symptomatic. Three main themes were generated through a thematic analysis of 23 interviews. The results identified positive changes to practice during the COVID-19 pandemic although concerns related to the adequacy of consultation taking place remotely and how this may affect the assessment of symptoms, delays in diagnosis, and challenges around managing the backlog of people referred.

The impact of COVID-19 upon cancer referrals, treatment and death rates has also been acknowledged by Cancer Research Wales (2021), who predicts that there may be an increase of 20% or more deaths related to cancer because of the impact of COVID-19. To address this in 2021 the Welsh government published guidance called the 'Quality Statement for Cancer' containing a five-year plan to improve the quality of cancer services and outcomes (Welsh Government, 2021). The guidance was published amid the COVID-19 pandemic and encompassed immediate, short-term, medium, and long-term development of services. The focus of the guidance was on equitable, safe, effective, efficient, person centred care and timely care (see table 1.2 below for more details and the highlighted areas related to the earlier diagnosis of cancer). Several aspects of the report specifically focus on the earlier diagnosis of cancer (i.e., that more cancer cases are identified earlier, more treatable stages with increased timely access to diagnostics investigations) and to reduce mortality rate with the 'Quality Statement for Cancer' (Welsh Government, 2021) stating:

“Over the past decade, cancers have been one of the most common causes of death in Wales and this is likely to remain so in the decades ahead due to the ageing nature of the population. It is vital that cancer is effectively prevented where possible, that cases of cancer are detected at earlier more treatable stages, and that complex treatment pathways are optimised: while throughout people are properly supported and co-produce their care. Ultimately, the aim is to improve population survival and reduce cancer mortality rates.” (p.1)

Table 1.2*Welsh Government 'Quality Statement for Cancer' 2021*

| Focus of the Report | Details of the Report Included (But not Exclusive to) |
|---------------------|--|
| Equitable | <ul style="list-style-type: none"> • Service improvement • Access and consistency in care • Monitoring (audit/ peer review etc.) to support accountability discussions • Horizon scanning, more rapid/ widespread local adoption • The cancer workforce is planned to meet the potential demand |
| Safe | <ul style="list-style-type: none"> • An immediate system-level in relation to pre-pandemic waiting lists • Targeted population screening programmes • The reconfiguration of cancer services which are fragile to meet more resilient regional/ national services • Integrated acute oncology service within acute hospital settings |

| Focus of the Report | Details of the Report Included (But not Exclusive to) |
|---------------------|---|
| Effective | <ul style="list-style-type: none">• Earlier increases of detection and timely access to diagnostic investigations• Surgical techniques, genomic therapies, radiotherapies systemic anti-cancer therapies routinely available• People who are eligible are offered access to research trials |
| Efficient | <ul style="list-style-type: none">• Both the single cancer and nationally optimised pathways are embedded as part of local services• That cancer patient records are on modern IT systems which facilitate an integration of data and care• Clinicians are supported in terms of working at the top of their license, to improve skills, engage within quality assurance research |

| Focus of the Report | Details of the Report Included (But not Exclusive to) |
|---------------------|---|
| Person-centred | <ul style="list-style-type: none"> • Care is person-centred and this is culturally embedded whilst assessing/ managing patients' needs • The use of co-production to ensure outcomes are achieved which matter to service users • Precision medicine • Pre-habitation/ rehabilitation |
| Timely | <ul style="list-style-type: none"> • Cancer services are measured/ held accountable in alignment with outcomes linked to quality patient care • Timeliness of cancer pathways are measured • Cooperation with national diagnostic programmes/ networks facilitates increased access to diagnostic investigations |

Hence, given current research, guidelines, campaigns, and clinical practice with regards to the earlier diagnosis of cancer, understanding how people enter into healthcare services is paramount. Understanding how people enter into healthcare services is in turn relevant to the topic of this thesis (as discussed below). Therefore, understanding what factors may influence this process for both classically known symptoms and also more vague, unexplained symptoms is important because it can

provide evidence in terms of what factors encourage or motivate people to enter into systems that may influence receipt of an earlier diagnosis of cancer. This Chapter will now, examine the historical literature in terms of healthcare service utilization to explore how previous literature has explored the topic.

Historical Approaches to Healthcare Utilisation

The reason why some people seek advice from healthcare services when they experience symptoms of illness, whilst other people do not has been of interest to researchers across many decades going back to the early 1970s (Anderson, 1973). The different historical approaches were outlined by Anderson and include the sociocultural approach, the socio-demographic approach, the organizational approach, and medical sociology, several of which are summarised below to provide context to this Chapter. A more recent social psychology approach will then be considered, leading to the exploration of a contemporary medical approach in relation to cancer research, then a health psychology perspective. The role of symptom recognition and lay referral (when lay members of the public interact with a friend, relative, or social network member with regards to their experience of bodily changes or illness symptoms) will also be considered in connection to the aims of this thesis and as part of the time frame between symptom recognition and help-seeking behaviour.

A Historical Sociocultural Approach to Healthcare Utilisation

Research-grounded within a sociocultural position advocate that healthcare services form part of a cultural complex that is situated within and dependent upon the cultural context of the services themselves. This also generally relates to other social institutions or different subcultures grounded within that particular society. Here, healthcare services, or hospital service delivery are greatly dependent upon the cultural context (i.e.- geographic location, religious context, economic institutions, and family) of the healthcare system itself which was thought to influence people's utilization behaviour within that particular society (Anderson, 1973).

This can be illustrated through the work of Irving Zola dating back to the 1960s. Zola (1966) highlighted the importance of socially conditioned processes and how social context may influence people's behaviour beyond that by aetiology alone. For example, Zola outlined how physical illness had previously been considered to

be objective in terms of clinical severity and how this did not mirror the high prevalence of physical illness, nor the low self-reports of symptom recognition, and how people's decision to gain healthcare advice was not always connected to the severity of symptoms. Therefore, Zola examined the role of socially conditioned processes (i.e., differences between different societies or subgroups) with a focus upon 'what the patient brings' to the doctors as opposed to previous research which examined the differences between similar illness or disease symptoms/underlying pathology. The aim was to investigate how cultural factors such as being part of a particular ethnic group influenced how symptoms were presented at the doctors by the patients, using open-ended interviews, and a series of measures, data were compared across two sample groups; an Italian sample (N=63) and an Irish sample (N= 81) (Zola, 1966). No significant difference was found between the groups in terms of the standard measures of social class, and medical coverage (insurance), with the Irish group perceiving increased poor health compared to the Italian group. However, although this perceived difference arose in terms of their health, in accordance with the doctors' ratings there was no difference in terms of the severity of symptoms across the two groups. In addition, the doctors thought and perceived that the Irish group's experiences were considered to be more urgent in reference to treatment. These results were amongst others as part of the study which highlighted the importance of expression during consultation from a cultural/ ethnic-group perspective. This was a classic study that is well cited, however, what was not captured as part of the qualitative data was the different group's interpretation of their experiences themselves (Zola, 1966). Therefore, although a valuable study in terms of how culture shapes these processes it may have been beneficial to also examine how the participants not only perceived or recognised their symptoms but also how they interpreted their experiences. Another criticism of this approach is that the focus was upon sociocultural factors alone without any acknowledgment as to how or if individual differences or factors (i.e., cognition, emotion) influenced these processes. This focus upon sociocultural factors alone demonstrates the dualistic nature of research which separated psychological/ sociological explanations during this historical time period in which social factors were considered in isolation.

A Historical Organizational Approach to Healthcare Utilisation. The organizational approach was different from the sociocultural approach and investigated the structures/ systems associated with the healthcare providers themselves (as opposed to structures linked to the service users and people who may access or engage with healthcare services). Consequently, the organizational approach explored structural comparisons between different services across multiple different countries or geographical locations. For example, Anderson (1972) (as cited in Anderson, 1973) examined healthcare services in England, Sweden, and the United States and reported differences between each of the three geographical locations. These differences related to the number of medical professionals in each setting, the number of hospital beds available within the different locations (i.e. in the U.S.A. it was claimed that services were 'over doctored'); length of hospital admission and also differences existed in the cost of healthcare services in each country. The organizational approach gained popularity in the field at the time due to its direct contribution to intervention strategies in terms of healthcare services. Despite the historical popularity of the organizational approaches given their direct applied nature, Anderson (1972) offered a critical perspective and outlined several limitations of the approach. These limitations were discussed as part of Anderson's (1972) paper titled '*Healthcare: Can There Be Equality?*'. The main point raised was how the increased costs associated with providing healthcare services created a change within the services themselves and in how they were experienced and delivered. These changes from a provider perspective were often viewed positively in terms of service delivery, although from an individual level these alterations often resulted in the depersonalization of healthcare from the service user's perspective. This highlights the potential differing agenda of those involved from a system-level position which may differ from those engaging with the services. This potential discrepancy between a system-level focus and individual-level focus is similarly dualistic in nature as was the sociocultural approach to healthcare utilization.

A Historical Critique of Healthcare Utilization Approaches. McKinlay (1972) nearly 50 years ago, conducted a systematic review of healthcare utilization literature where several issues arose, these issues referred to how the reported empirical findings often claimed to be more substantial than the actual findings themselves; research in the field lacked consistency, the research did not explore

nor explain disparities, and research, especially in Great Britain, lacked a sound theoretical foundation in regards to utilization of behaviour itself. McKinlay attributed these limitations to the different methodological approaches used, and the diverse range of interpretations grounded within different perspectives during this time period. Based upon the divergent nature of the literature, McKinlay reported possible useful variables for exploration to move beyond the restraints of previous utilization behaviour research. These included a methodological shift to include small exploratory inductive studies to build upon population level research; a more in-depth examination (beyond descriptive reports) of social-psychological factors and how research could investigate utilization behaviour/ under-utilizers/ overutilization of healthcare services; and the exploration of how social networks, family, intra-family patterns and friends also influence utilization behaviour in the context of healthcare (McKinlay, 1972). These recommendations, therefore, move away from a dualistic approach and conceptualisations of people's behaviour thus suggesting a more individual-level focus.

The Historical Shift from the Socially Oriented Utilization Behaviour to the Psychosocial Concept of Delay. Research examining why people seek healthcare advice or not when they either experience illness symptoms have a historical position in the literature as outlined above (Safer, 1979). However, there has been a shift in the way in which this area is thought about, studied, and conceptualised. The study of utilization behaviour from a dominant social perspective with the main focus upon social factors changed in the late 1970s to the study and conceptualization of behavioural 'delay'. Safer (1979) highlighted how 'delay' was conceptualised as the 'total time elapsing' from when a person first noticed a symptom until they gained or sought healthcare advice. Therefore, during this shift, the focus of research changed from questioning 'why people in different social groups or subgroups engaged with healthcare services to exploring factors associated with 'why there may be differences associated with behavioural 'delay' as well as engagement' (Safer, 1979). However, just as the utilization literature from a dominant social perspective met criticism as outlined by McKinlay (1972) previously, so did the conceptualisation of behavioural 'delay' in terms of 'time elapsing'. This criticism referred to how 'time elapsing' as a measurement of behavioural 'delay' may hold multiple similar or different influencing or confounding factors for different

people. For example; people may interpret different bodily changes in differing ways, thus questioning what constitutes an illness symptom that requires healthcare advice and how this affects these processes. This in turn indicates that the underlying processes or factors which shape symptom recognition may not be the same as those which mediate or influence a period of delay in regards to help-seeking behaviour (Safer, 1979).

Based upon this, Safer (1979) developed a three-stage model of delay in connection to the time frame between noticing a symptom and consultation for healthcare treatment. The three different stages of the model may include a period of delay and each stage is comprised of three separate processes and factors which may influence these time frames. The three stages were: the *appraisal delay* (where the person appraises their experience of bodily sensation/ illness symptom and considers if they feeling ill or if there is something wrong); the *illness delay* (the person considers if they need medical or healthcare advice) and the *utilization delay* (the person decides if gaining medical or healthcare advice/ consultation could be beneficial and considering any barriers to gaining access to services). As part of the rationale in terms of the development of the model itself, Safer (1979) claimed that the three-stage model was able to examine much broader psychological and social factors. For instance, the key variables of the model were the dependent variable of 'types of delay' (i.e.- 'total delay', the time frame between noticing a symptom and healthcare consultation; with 'total delay' separated into the three stages of 'appraisal delay', 'illness delay' and 'utilization delay') and the independent variable of 'predictors of delay'. The following 'predictors of delay' were: sensory and/or perceptual experiences; self-appraisal of symptoms; coping responses; emotional responses; imagined consequences of the symptom and situational barriers.

Each of the three stages of delay offered explanatory value in regards to the predictors of the length of 'delay' between the different stages of the model. The predictors for the first stage 'appraisal delay' were perceptual and /or sensory factors (i.e.- pain or fever, location of sensation, frequency, severity, interpretation, evaluating symptoms, coping strategies, and behavioural action such as home remedy or information seeking). Regarding the second stage 'illness delay', beliefs, emotion, and imaginary factors of the symptoms (severity, emotional arousal linked to these beliefs/ increased negative affect either increase health behaviour or increase avoidance); whilst the third stage uncovered situational, contextual, and

socio-demographic factors (age, sex, education, family composition, race, barriers to access to services, and treatment beliefs). The three stage model of delay in turn encompassed much broader psychosocial factors which moved beyond the exploration of social factors in isolation. However, Safer (1979) explored the model which uncovered the complexity of factors involved and found difficulty predicting how each of these factors in isolation or in combination influenced the overall measure of 'total delay'. Given the complexity, Safer (1979), concluded that the relationship between these different factors may depend upon the aim of the research itself. For instance, research could explore one aspect of the model or the overall time frame in terms of 'total delay'. Therefore, although the three-stage model of delay (Safer, 1979) made an important historical contribution to the literature by integrating both broader psychological and social factors, Safer (1979) highlighted how the results of the empirical testing of the model should be interpreted with caution. Other limitations also arose associated with Safer's study in terms of the use of quantitative measures which did not capture contextual or experiential aspects of people's experiences, and furthermore, the sample population involved people who experienced varying mild symptom complaints (i.e., muscular pain, respiratory disease) signifying that the sample population was not matched based on the same physical symptoms which may have elicited differing responses.

More Contemporary Models in the Context of Cancer Research

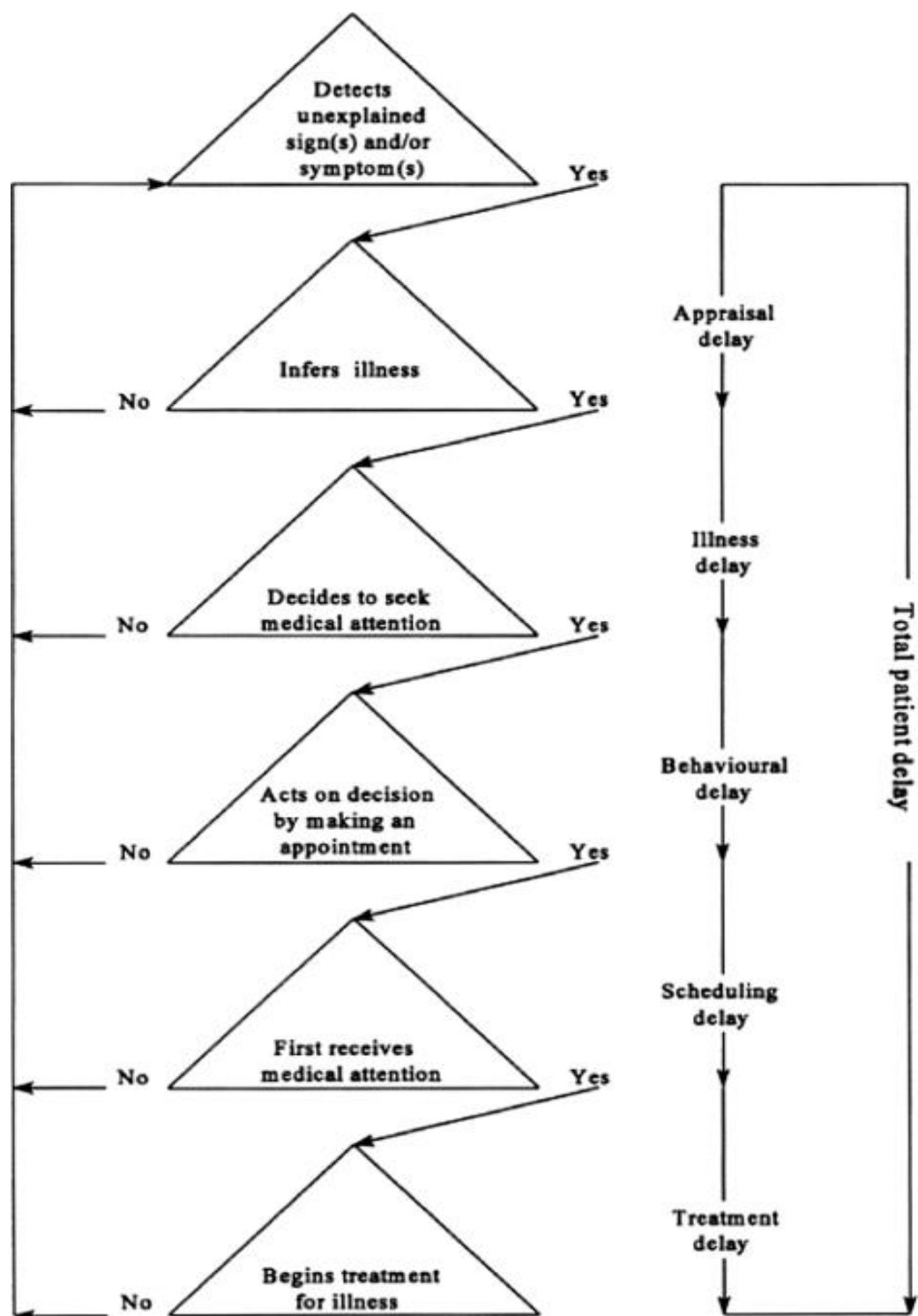
A Social Psychology Perspective; The Anderson Model (1995)

More contemporary models have also considered 'delay' in the context of cancer research. This can be exemplified by the work of Andersen who created the General Model of Total Patient Delay (Andersen et al., 1995). The proposed five-stage model includes different 'patient pathways' that examined factors associated with periods of time delay in terms of people receiving a cancer diagnosis (see Figure 1.1). The model examines *appraisal delay* (the time between when a person identifies an unexplained symptom and subsequently associates this with being ill); *illness delay* (the time frame between the onset of illness and the decision to gain medical advice e.g. booking an appointment); *behavioural delay* (the time frame between the decision to gain medical advice and action); *scheduling delay* (the time between behavioural action and physically attending an appointment, although this

could be out of the individual's control) and *treatment delay* (the time between the first appointment with a medical professional and the start of treatment) (Andersen et al., 1995).

Figure 1.1

A General Model of Total Patient Delay



Source: Andersen et al. (1995) <https://doi.org/10.1111/j.2044-8309.1995.tb01047.x>

Andersen et al. (1995) published an article in the British Journal of Social Psychology with regards to the General Model of Total Patient Delay. Two different sets of analyses were presented in reference to diagnostic ‘delay’ making reference to the above model. The analysis also focused upon how people attribute their symptoms to knowledge and expectations of physiological processes, based upon Psychophysiological Comparison Theory (PCT) which provided a foundation for appraisal and interpretation. See the below table 1.3 for more information about the theoretical aspects and principles of PCT as outlined in Andersen et al. (1995).

Table 1.3

Principles of Psychophysiological Comparison Processes

| Principles | |
|---------------------------------|---|
| Assumptions | <ol style="list-style-type: none"> 1. People are motivated to maintain an explicable physiological condition. 2. Symptom perception need not be accurate in terms of physiological aetiology. |
| Antecedents | <ol style="list-style-type: none"> 3. The strength of the motivation to understand and evaluate one’s symptoms is a function of their unexpectedness, salience, personal relevance, and perceived consequence. |
| Psychophysiological comparisons | <ol style="list-style-type: none"> 4. Symptom interpretation involves a comparison of the symptoms with the known consequences of salient situational stimuli (e.g. exposure to pathogens, recent medications) and physiological conditions (e.g. allergies, diseases, that is, illness prototypes). |

Principles

5. Symptom interpretation is governed in part by logical consistency. For example, the probability of a specific illness inference is a direct function of its accessibility (familiarity) and an inverse function of the discrepancy between the symptom and the illness prototype.
6. Symptom interpretation is governed in part by an optimistic bias. For example, innocuous explanations (e.g. prototypes which suggest the symptoms are transient or self-correcting) diminish an individual's motivation to obtain additional information or explanations for the condition to a greater degree, *ceteris paribus*, than to threatening explanations.
7. The more diffuse the symptoms, the greater the number of potential comparisons, and consequently, the greater the likelihood of erroneous interpretations of the symptoms and the more susceptible to change are the interpretations.

Effects of failing to find a comparison

8. If a situational stimulus or illness prototype cannot be initially identified to account for the symptoms, then the stimuli or prototypes(s) which maximizes the logical and optimistic bias principles above will be considered. This will influence

Principles

the subsequent symptom interpretation process in at least two ways:

- The implicit theories people have about stimuli or prototypes will influence the attention to and detection of symptoms and the production of symptoms for interpretation/
 - The particular symptoms chosen will influence people's implicit theories about stimuli or prototypes.
-

Source: Andersen et al. (1995) <https://doi.org/10.1111/j.2044-8309.1995.tb01047.x>

Of Andersen's studies, the first study explored women who had been newly diagnosed with gynaecological or breast cancer and the second focussed on those who had not yet received a diagnosis. The results of the first study supported the five different intervals across the model and that 'appraisal delay' in which the women interpreted their symptoms created a high level of delay. The results also supported the PCT principles (amongst other findings) and demonstrated difficulties around the interpretation of bodily stimuli when symptoms represented more general symptoms. Andersen et al. (1995) outlined how these results were in contrast to research that had been conducted before this study in terms of the low predictive value found for more socio-demographic variables. The second study supported the first in terms of the model and again indicated that 'appraisal delay' related to the women's delay in connection to seeking healthcare advice when they experience breast cancer symptoms, but were unaware of the clinical significance.

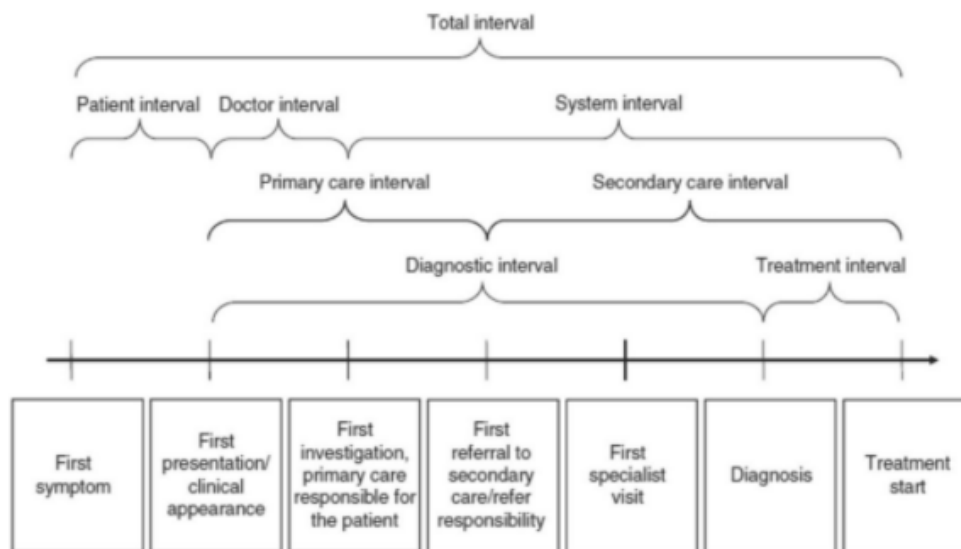
The contribution of the General Model of Total Patient Delay (Andersen et al., 1995) was one that integrated social psychology theory into the field of cancer research supported by empirical research. Following the development of the General Model of Total Patient Delay 26 years ago, the model has been used in cancer

research to identify and show the different delay intervals within and across the different stages of decision-making (e.g., when people infer illness, decide to gain healthcare advice) and healthcare systems (i.e., the initial management in primary care services) (Walter et al., 2012). However, in accordance with Walter et al. (2012), who conducted a systematic review of the literature that had drawn upon the General Model of Total Patient Delay when conducting cancer research, they found that although the model had been used, it had not been applied in conjunction with psychological theory as a framework in which to understand these processes. These findings reinforce previous critique in terms of how the Andersen (1995) model has been used, without the original integrated psychological theory.

A More Contemporary Medical Perspective; The Aarhus Statement (2012)

The way in which people enter healthcare systems has not only been examined in the social and psychology literature but also in the medical literature. For example, Weller et al., (2012) published the Aarhus Statement in British Journal of Cancer (2012). The Aarhus Statement (2012) outlined how an increased understanding is needed in reference to the pathways in which people enter healthcare systems before diagnosis. Here, the Aarhus Statement (2012) reiterated similar issues that had been previously highlighted by McKinlay (1972) nearly 50 years ago in terms of utilization behaviour, although the focus of the Aarhus Statement was on cancer research. The Aarhus statement discussed the lack of conceptual/theoretical/ methodological consistency in the existing literature, which creates challenges when comparing the findings.

To try to move beyond these limitations, the Aarhus statement outlined a set of definitions and methodological recommendations for those conducting cancer research. These recommendations were encompassed within a researcher checklist and were developed from a consensus group and data derived from a systematic review. The definitions described in the Aarhus statement related to and detailed what is meant by the following stages: 'date of the first symptom', 'date of the first presentation', 'date of first referral', and 'date of diagnosis' across the patient journey (see figure 1.2).

Figure 1.2*Cancer Diagnostic Intervals used in Developing the Aarhus Statement*

Source: Weller et al. (2012) <https://doi.org/10.1038/bjc.2012.68>

The Aarhus Statement also presented methodological recommendations in reference to how to collect primary data from service users/ providers; case-note audit; and primary-care database analysis. These methodological recommendations were based upon the rationale that a high majority of previous research had been retrospective which the authors thought highlighted issues of recall bias. Instead, they suggested prospective research, whilst acknowledging the challenges faced by researchers conducting prospective studies in terms of gaining and retaining large samples. Other challenges were discussed linked to sampling/ the timing of recruitment in terms of people's diagnostic journey and treatment, with the emotive aspects of these experiences outlined. The suggested methods aimed to increase transparency and validity and to reduce recall bias using strategies such as calendar landmarking during qualitative interviews to prompt recall of events etc.

However, whilst the Aarhus Statement offers a comprehensive guide for researchers, it also has limitations. For instance, issues around measuring 'time' in connection with these intervals across different patient pathways have previously been critiqued in the traditional literature, as a potential confound measure of the time frame (i.e., Safer (1979) 42 years ago as discussed above). The methods proposed although helpful in terms of plotting the intervals in connection to the pre-defined system-level milestones (e.g., patient interval) appear not to capture any social factors or psychological individual differences (cognition, emotional factors, etc.) in isolation or combination. Therefore, although the Aarhus

Statement utilises more contemporary healthcare systems as part of the data collection process, the statement itself does necessarily move away from some of the historical critiques in the field in terms of system-level approaches. The Aarhus statement as a paper also opens itself up to critique about the underpinning assumptions associated with working across, between, or within paradigms (qualitative/ quantitative) and does not clearly state the orientation or epistemological position of the recommendations of the paper (i.e. - when discussing recall bias in qualitative interviews).

Coxon et al. (2018) reinforced the above critique with regards to the methodological measurement of patient pathways and/ or intervals in connection to cancer diagnosis (Coxon et al., 2018). Here, Coxon et al. (2018) referred to the 2012 article and note how there is still an ongoing issue with the quality of research published in connection with measuring instruments in the field of cancer research. This again highlighting current methodological issues in the field in reference to the measurement of people's experiences, the complexity of people's diagnostic journey, and the challenging nature of cancer symptoms which are often multiple and vague (Coxon et al., 2018).

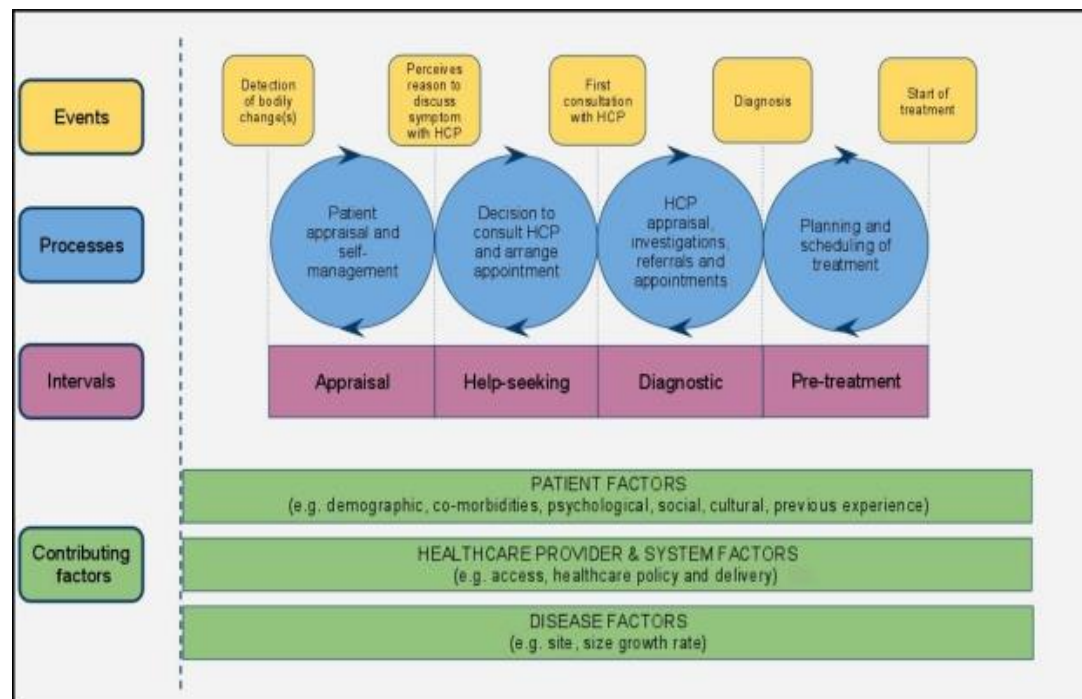
A More Contemporary Health Psychology Perspective; Model of Pathways to Treatment (Scott et al., 2013)

Other models that have been developed are the Model of Pathways to Treatment (Scott et al., 2013) (see figure 1.3). The Model of Pathways to Treatment aimed to build upon the Andersen (1995) General Model of Total Patient Delay; which in more recent years has been applied in research without any theoretical consideration although was considered in the context of social psychology theory to enable explanatory value. Scott et al. (2013) not only aimed to build upon the Andersen (1995) model but offered a critique in terms of the limitations of the model. Some of these limitations related to:

- Symptom recognition; with Scott et al. (2013) highlighting how the starting point of the Andersen (1995) model does not account for any delay in terms of the late perception of bodily changes that may be dismissed as normal, rather than as a 'symptom'
- Cognitive factors are considered in reference to symptoms perception and interpretation, but not emotional factors

- That the Andersen (1995) model is linear, and does not represent the more dynamic, complex process that may take place across or within each of the intervals
- The Andersen Model (1995) does not encompass different coping responses (i.e., seeking lay advice, self-medicating etc.) that may be elicited when experiencing bodily changes or potentially cancerous illness symptoms.

Therefore, The Model of Pathways to Treatment offered a revised framework, reconfigured pathway stages, and explained the different conceptual definitions of each stage from a psychological perspective. In consequence, the model utilised psychological theory to explain potential factors that may influence illness behaviour when people experience potentially cancerous illness symptoms across symptom recognition, the diagnostic, and treatment journey. This main overall focus of the Scott et al., 2013 paper related to the appraisal and help-seeking interval which moved beyond the historical literature by acknowledging the potential biological (disease factors); social/ psychological (patient factors), and system level factors (access to healthcare, etc.) that may shape these processes.

Figure 1.3*Model of Pathways to Treatment*

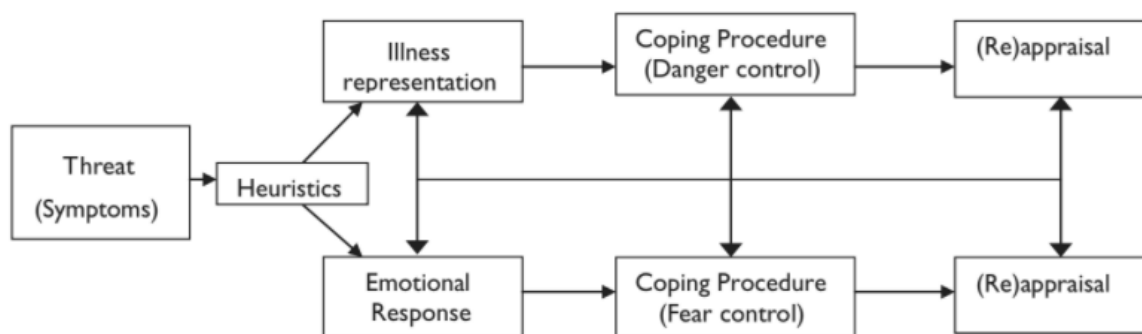
Source: Scott et al. (2013) <https://doi.org/10.1111/j.2044-8287.2012.02077.x>

Scott et al. (2013) drew upon existing psychological theory as a way in which to explain the potential processes as part of the appraisal and help-seeking interval. The Common Sense Model of Illness Self-regulation (CSM) (Leventhal et al., 2016) (see figure 1.4) and Psychophysiological Comparison Theory (as discussed as part of Andersen 1995) were theoretically described and presented a theoretical way of understanding appraisal and coping processes from a health psychology perspective. For example, Scott et al. (2013) suggested that after people have detected bodily changes/ somatic information there is an automatic cognitive assessment of the level of salience, relevance, and the potential consequences of the bodily change(s). Those bodily changes that are not assessed or expected to interfere are normalized to enable adaptive functioning. In accordance with Scott et al. (2013), this may provide explanatory value in terms of delay as these typically adaptive cognitive processes which facilitate continued functioning may or may sometimes create a delay in terms of bodily changes being recognised as potentially cancerous illness symptoms and help-seeking behaviour. However, in terms of

people interpreting bodily changes as illness symptoms Scott, et al. (2013) indicates that CSM theoretically draws upon heuristics (automatic or deliberate cognitive processing) when interpreting bodily changes. Thus, implying that cognitive processes (amongst other factors i.e., emotional) such as heuristics shape what represents an illness symptom (illness representations) and influence how people make sense of their experiences (in terms of the identity of the bodily change as an illness symptom; the expected timeline that it may last, the consequence of the illness symptoms, people control and how they get better) and if they need to gain professional healthcare advice.

Figure 1.4

Leventhal's Common Sense Model of Illness Self-Regulation



Source: Scott et al. (2013) <https://doi.org/10.1111/j.2044-8287.2012.02077.x>

The help-seeking interval was considered through a theoretical 'coping' lens in response to illness perceptions (associated with the domains of consequence, timeline, identity, illness concern, and emotional representation). Scott et al. (2013) referred to coping in the context of behavioural responses in connection to health threats (i.e., self-treatment, monitoring symptoms, and seeking medical help) to control danger or fear; rather than broadly linking coping to the problem and emotional focused coping alone. In alignment with CSM, the social context was considered as a potential influence on self-regulation, with self-regulation thought to be influenced through the input and/ or advice of others. Social sanctioning from a Social Cognitive Theory (SCT) perspective was discussed in reference to how other

people may shape people's feelings/ perceptions in terms of the need and permission to gain healthcare advice. The interplay between how socially learnt schemas or representations from other people and how this may not reflect the lived experience of the individual was also discussed. This highlights the multifaceted bidirectional nature of SCT, and how internal personal factors (cognition, biology, emotion, and thought processes) interact with the external social environment, thus holding the potential to influence individual behaviours and people's cognitive thought processes (Bandura, 1989).

These relational and social factors also include how social interactions with other people who model social behaviours project social persuasion, providing external sources of observational vicarious learning. The process of observational vicarious learning is embedded within the surrounding social context, with social models displaying behaviours that induce newly acquired individual behavioural patterns that occur in parallel to altered personal cognitive thought processes. External social modelling in turn does not only directly affect individual behaviour, but reciprocally modifies psychological functioning associated with individual motivations and variants of internal emotional arousal. For example; social models exhibit social behavioural instruction that provides observational learning and externally encourages or discourages behavioural action; consecutively leading to a wide spectrum of personal emotional arousal. Personal self-arousal then concurrently modifies cognitive thought processes and psychological functioning. Here important modification can also arise from the external social model's emotional response to the individual's behaviour, this is known as vicarious affective learning (Bandura, 1989). Therefore, SCT acknowledges that observational learning, psychosocial functioning, and behaviour vary across diverse social practices and experiential conditions. This variation of observational learning, in addition, affects the cultivation of personal self-efficacy (the individual's perceptual belief of their ability to succeed within certain tasks or situations) with lower self-efficacy potentially reducing behavioural motivation/action and higher self-efficacy increasing motivational beliefs for behavioural action (Bandura, 1989). Here, Scott et al., (2013) suggested that self-efficacy was also a factor that may shape people's help-seeking (their perceived ability to discuss their experiences/ gain support from the healthcare professionals) in conjunction with potential service barriers and how outcome expectations (physical, social and self) also shape these processes. Overall, the theoretical

complexity of symptom appraisal and help-seeking was exemplified through theories that could account for the interactive nature of people's cognition, emotion, and social context. Consequently, Scott et al., (2013) made the following recommendations for future research:

- To validate the Model of Pathways to Treatment
- To explore the role of heuristics or to test de-biasing strategies
- To explore the psychological concepts outlined (i.e., SCT concepts such as self-efficacy)
- To assess barriers/ triggers across differing diseases or healthcare systems.

Summary

The utilization of healthcare services, delay, and if, how, or when people enter into healthcare has been the topic of much research over the last 55 years. The majority of early research took a social position with a move towards an integrated/ interactive psychosocial understating of the potential processes in more contemporary health psychology theory and cancer related papers. Therefore, the studies reported in this thesis aim to address existing limitations in the field and to increase our understanding of the time frame between symptom recognition and help-seeking, as presented below.

Aims of the Overall Thesis

The overall aims of the thesis are described below:

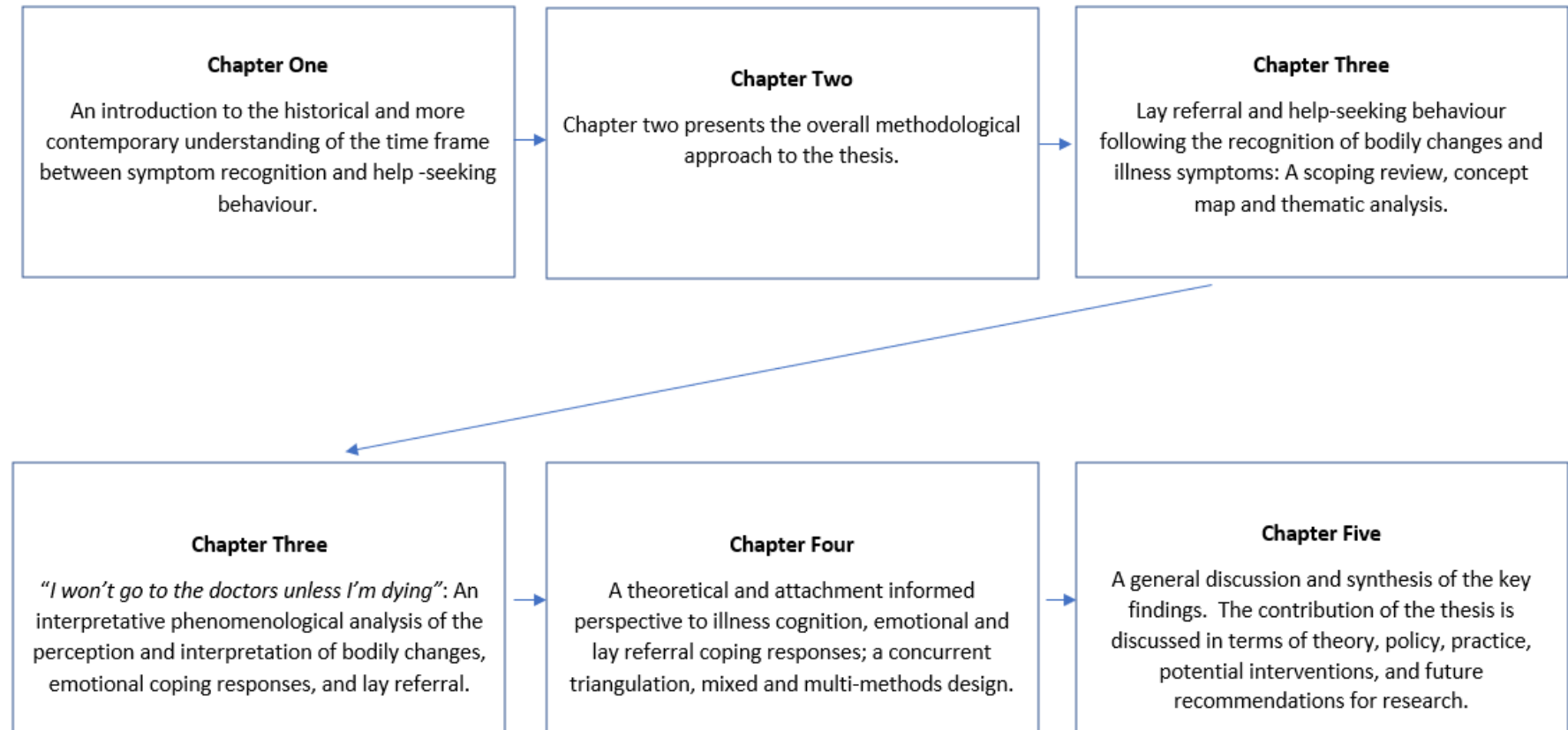
- To build upon the previous literature
- To take a psychosocial rather than a dualistic approach to the topic and
- To explore what factors, influence the time frame between symptom recognition, lay referral and healthcare professional help-seeking behaviour in response to bodily changes that may or may not be cancerous illness symptoms.

In consequence, the studies which form the thesis did not aim to focus on either the 'utilization', 'under-utilization' or the 'overutilization' of healthcare services; nor did

the studies situate the topic purposefully within factors associated directly with the measurement of 'delay' across or within the intervals. Rather the thesis aimed to topically explore symptom recognition, emotional coping responses, lay referral, and potential help-seeking across both intervals (i.e., 'appraisal'/ 'help-seeking'). The specific focus on lay referral was considered to increase the psychosocial focus of the studies; to enable the development of the concept following the 1970s, and to build upon CSM/ The Model of Pathways to Treatment that have previously acknowledged social factors in the context of health and illness.

Conclusion

In order to describe how the above aim of this thesis will be met, Chapter two will present the overall proposed methodological design of the thesis. Here, an exploratory mixed methods design will be discussed concerning the topic, and how this design addresses some of the existing limitations in the field and current gaps in knowledge. In doing so we seek to extend our understanding of the time frame between symptom recognition and help-seeking behaviour when people may experience bodily changes that may or may not be cancerous illness symptoms. The below thesis map (figure 1.5) visually outlines each of the Chapters which form part of this PhD thesis.

Figure 1.5*Thesis Map*

Chapter Two

Methodological Approach

Methodological Approach

Introduction

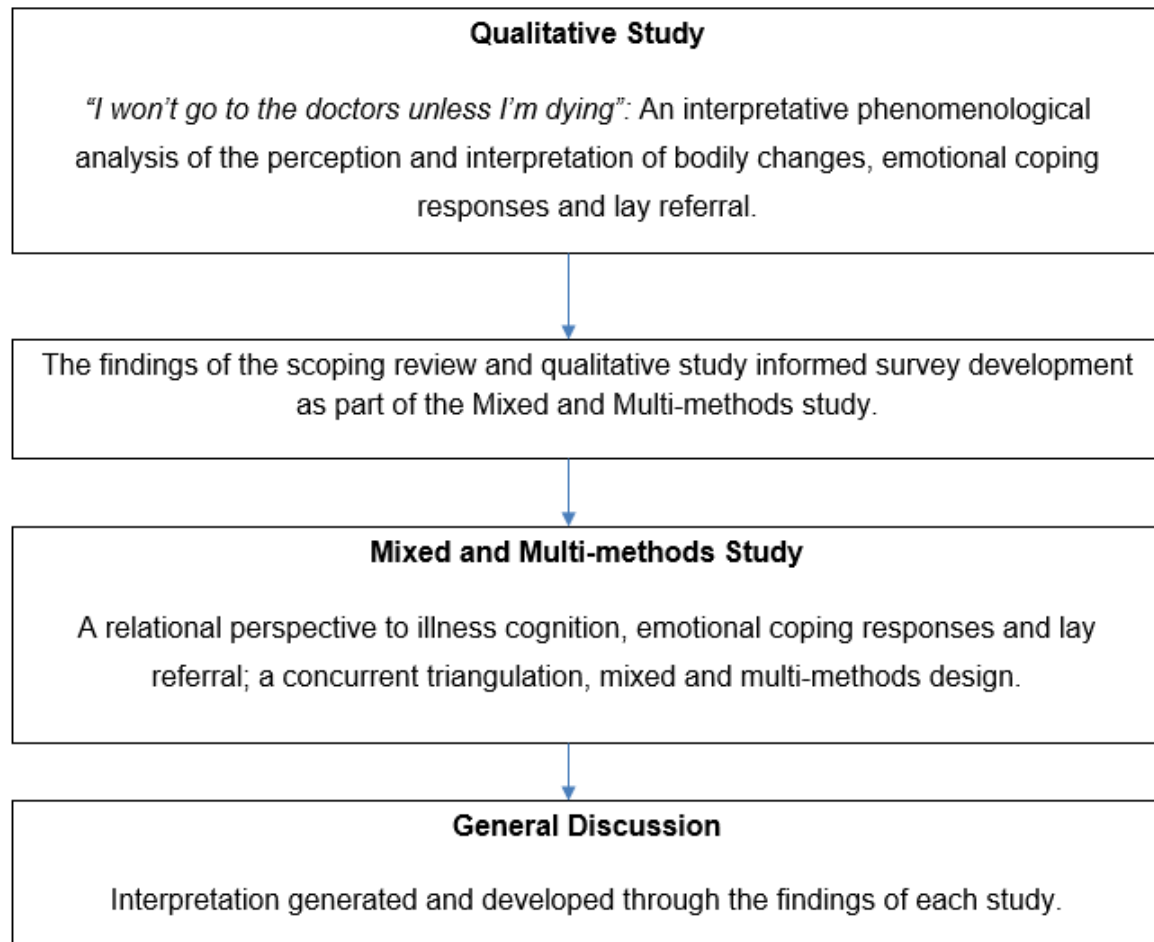
This Chapter will introduce the reader to the methodologies used as part of this thesis and how these approaches relate to the time frame between symptom recognition and help-seeking behaviour. Here, the overall research paradigm of the thesis will be discussed, the adapted exploratory design, how the design relates to the phenomena, the epistemologies of the work, and the quality criteria checks which were drawn upon.

The Research Paradigm of the Overall Design of the Thesis

Scientific knowledge derived from mainstream psychology has historically and is often still currently situated within empiricist and observable quantitative experimental methods. These methods often focus upon the objective measurable aspects of human behaviour which align with those used in the natural sciences (Shaw & Frost, 2015). In consequence, the historical application of experimental methods in mainstream psychology left many psychologists unable to answer existential questions related to the meaning of people's experiences beyond hypothesis formulation and empirical testing (Schiff, 2019). However, following the postmodern movement in the 1970s that argued against cognitive reductionism, feminist psychology, and the introduction of qualitative methods; alternative ways of thinking in psychology arose grounded in the philosophical traditions (Yardley, 2017). These philosophical traditions included: phenomenology, pragmatism, and constructivism which advocated that the knowledge we gather (either as a researcher, person, or a participant) is situated, shaped, and constrained through our own perspective, language, socio-cultural context, and world views (Yardley, 2017). This shift in terms of pragmatism was also apparent in other disciplines such as health and/ or social research in connection to mixed methods research (Morgan, 2014). Therefore, in order to move beyond mainstream methods alone in connection to psychological research the overall position of the thesis will take a pragmatic position drawing on pragmatism and mixed methods (Creswell, 2013). Pragmatism can be defined as a philosophical approach that creates knowledge based upon the practical aspects of the research questions in connection to the topic of interest (Creswell, 2013). The flexibility of a pragmatic approach was considered to be

important as it enabled the use of different methods with differing underpinning assumptions to build knowledge study by study in accordance with each of the research questions. The overall design of the thesis is outlined below with each of the methods used discussed in more detail as part of the methods section in each separate Chapter.

An Adapted Exploratory Design. The overall design of the studies presented in Chapters four and five used an adapted version of the mixed methods exploratory design (Creswell, 2013) (see figure 2.1 below). This adaption had two parts that utilised the findings of the qualitative component to shape the final mixed and multi-methods study. This included a survey development stage informed through the scoping review and qualitative results in Chapter four. The sequential nature of the design was considered to be an advantage, building upon the findings, as opposed to the survey design being completely researcher-led (Creswell, 2013). Therefore, this design offered a range of different epistemological assumptions across the thesis that did not solely aim to control for environmental factors, but instead embraced the interconnected nature of the individual in the wider socio-cultural context (Camic, Rhodes, & Yardley, 2003).

Figure 2.1*An Adapted Exploratory Design*

The Phenomena. The above adapted exploratory design was considered important to ensure that the thesis took an inductive approach to the topic of the time frame between symptom recognition, emotional coping, lay referral, and professional healthcare help-seeking behaviour. In relation to symptom recognition, there was a focus upon the concept of ‘bodily changes’ as opposed to illness symptoms categorised by the medical model from a social psychology perspective (Radley, 1994). From this perspective, the assumption is that people’s perceptions in regards to illness are shaped through their own individual personal experience of illness, with their understanding of medical knowledge grounded in their wider understanding of the world in which they live (Radley, 1994). People in turn experience or become ill in a cultural backdrop of cognitive beliefs concerning good or poor health. The

difference between bodily signs and symptoms of disease according to Radley (1994) is situated in the cognitive recognition and interpretation of bodily changes as illness symptoms. The recognition of bodily changes (which may not be symptomatic of disease) as illness symptoms does not necessarily reflect medical classifications of disease. Instead, Radley (1994) proposed cultural patterns of illness behaviour anchored in the way that family members respond to illness and health. The family, who may or may not hold medical knowledge, in turn, influences the way in which bodily signs are understood as illness symptoms that require healthcare professional advice. Therefore, from this perspective, it was paramount to take an inductive mixed methods exploratory approach when exploring symptom recognition, emotional coping responses, lay referral, and help-seeking behaviour. The use of different methods in connection to the topic and research question(s) supports the production of different types of knowledge which was thought to extend our understanding of the phenomena (Creswell, 2013).

The Epistemology and Epistemologies of the Work. The overall epistemology of the thesis was situated in a pragmatic approach. This enabled a flexible approach to the sequential exploratory design of the overall thesis, with each of the studies drawing on different ontological assumptions and epistemological frameworks. Through this process, it was recognised that these different epistemological frameworks may either contradict, co-exist, or complement each other, although the overall aim was to address the research questions in connection to the topic (Creswell, 2013). For example, Chapter four presents an IPA study situated within contextualism with the aim of interpreting how people themselves make sense of their lived experiences in the social-cultural context (Larkin et al., 2006). This is different from Chapter five which drew upon a theoretically driven pluralistic framework, that incorporated both a mixed and multi-methods design. Here, this pluralist approach referred to the use of different quantitative and qualitative methods which differed in terms of how the data was collected and how the analytical process was applied (Frost et al., 2011). This approach was important to build upon the inductive nature of Chapter four, with Chapter five encompassing abductive reasoning which was considered appropriate and best suited to address the complexity of the theoretically-driven research question. For more in-depth

information about the methods, ontology, and epistemology of each study, please see each of the Chapters.

Quality Criteria and The Empirical Studies

The below section will outline how the use of quality criteria has been drawn upon in connection to the empirical studies. This also includes a discussion about the role of reflexivity and how reflexivity has been used differently in reference to Chapters four and five.

Quality Criteria and the IPA Study

Given the subjective nature of IPA as a form of qualitative inquiry, typical quality criteria that may be applied to more objective quantitative mainstream psychological research were not necessarily considered the goal of this study (i.e., reliability/ validity). For example, this can be exemplified when thinking about generalizability which some qualitative researchers argue is not the goal of this line of inquiry (Braun & Clarke, 2013). This is especially the case in terms of IPA given the idiographic focus which captures an individual snapshot of information at one moment in time. Thus, highlighting that the goal of IPA was not to generalise but to offer an in-depth insight into the participants' thoughts, perceptions, and feelings about a topic at that one moment in time. Instead, there was a move towards the '*trustworthiness*' of the study and the research findings (Frey, 2018). Here, the concept of '*trustworthiness*' can be defined as a broad concept that refers to the procedures a researcher may use to indicate the quality and credibility of their work (Frey, 2018). This can be worked towards in several ways as described by Yardley (2000) when considering what the characteristics of good quality qualitative research entail (see table 2.1):

Table 2.1*Yardley's Characteristics of Good Quality Qualitative Research*

| Characteristics | |
|----------------------------|---|
| Sensitivity to context | Theoretical; relevant literature; empirical data; sociocultural setting; participant's perspectives; ethical issues. |
| Commitment and rigour | In-depth engagement with data; methodological skill; thorough data collection; depth/ breath of analysis. |
| Transparency and coherence | Clarity and power of description/ argument; transparent presentation of data; fit between theory and method; reflexivity. |
| Impact and importance | Theoretical (enriching understanding); sociocultural; practical (for community, policy, healthcare workers). |

Based upon Yardley (2000) and Smith et al., (2009) the quality of the IPA study was considered through several procedures and stages. The first was related to how the researcher was 'committed' to the research process and 'rigour'. Rigour included the design process itself with regards to sampling in connection with the developed research question, how the researcher developed her interview skills through an iterative interview pilot process, and the researcher's commitment to the overall study. The second procedure to increase the quality of the IPA study related to how the first interview transcript was subject to a mini 'independent audit' conducted by a peer researcher. This enabled the examination of the analysis and the exploration of

the creditability of the themes (i.e.- how well-evidenced the themes were). This was not considered to be comparable to an inter-rater reliability check (from more of a mainstream/ positivist position) but rather aimed to reflect:

- The exploration of ‘sensitivity to context’
- The ‘commitment and rigour’ of the analysis and
- The ‘transparency and coherence’ of the work.

During this process, the peer researcher provided feedback and a verbal discussion took place in reference to the analysis of the first transcript. The third procedure related to the researcher sharing the overall main themes table with her expert supervisory team. Here, verbal and written feedback was provided during supervision. This feedback related to how the main themes connected to theory, the previous literature, how well-evidenced the themes were in the data, how the themes reflected lived experience, the strength of the researcher’s analysis and proposed arguments. Transparency and coherence were also considered to ensure that the research process was clearly outlined as part of the Chapter write-up. The overarching aim of the study was to inductively explore the topic with a focus on gaining experiential insight (Smith et al., 2009; Nizza et al., 2021). This was an important aspect of the thesis which was further discussed in terms of impact in conjunction with the mixed and multi-methods study as part of the General Discussion Chapter.

Reflexivity as Part of the IPA Study. Several levels of reflexivity were involved as part of the IPA study. The use of reflexivity from a quality perspective was considered important as described by Yardley (2000). An intersubjective reflexivity took place following each interview (in handwritten note form). This was based upon the researcher’s interest in reflexivity and the work of Finlay and Gough (2003). However, these notes have not been included within the study write-up as part of this Chapter, but instead were drawn upon during the analysis process. This was to ensure that the analysis process was firstly grounded in the participants’ data before the researcher’s second-order sense making. The researcher also explored the influence of her psychological educational background (BSc psychology/ MSc psychological research), previous healthcare service employment for over a decade, and how this may have also shaped her differing perspectives. Again, these notes

have not been included as part of this thesis but provided an opportunity to consider her role in the process and how her own previous experiences may have shaped her work. Reflexivity became a meaningful reflective method in which the researcher was able to continuously learn, note her thoughts, ideas, and feelings whilst considering the analytical approach.

Quality Criteria and Survey Development. In accordance with the overall adapted explanatory design of thesis, the inductive findings generated through the IPA study informed the focus of the bespoke survey developed as part of mixed and multi-method study (Creswell, 2013). To increase the quality of the study several stages of survey development took place. These stages included the below:

- The identification of the topical domain/ concepts for exploration in terms of item generation (through the literature review/ qualitative results)
- Item generation and the development of the item pool
- The examination of content validation (to explore if the items relate to the topical domain of interest). This was examined by an expert panel and through a selection of people who were considered to be part of the target sample population
- The survey questions underwent a pilot as part of the wider study process where the questions were pre-tested and feedback gained. The questions were developed and re-defined post feedback
- The pilot facilitated an assessment of the survey administration and
- A power analysis was run in connection to the wider battery of measures (Boateng et al., 2018).

Quality Criteria the Mixed and Multi-method Study. As part of the quality checks for this study, several different procedures were conducted as outlined below:

- The *a priori* of themes were discussed with the researcher's supervisory team. This allowed the researcher to discuss the *a priori* of themes and how they linked to the literature. This process allowed the researcher to consider Yardley's

'sensitivity to context' in terms of good quality qualitative research and how the *a priori* of themes linked to the existing literature.

- The clarity of the templates were explored and how they encompassed the data. A discussion with the researcher's supervisory team was also held in connection to theme development. This discussion offered an opportunity to explore what Yardley (2000) described as 'commitment and rigour' when considering how the researcher engaged with the analytical strategy, the data, and the breadth/ depth of the analysis.
- After the final template was formulated, a peer researcher examined the final template in connection with the lay referral data, who considered how the themes related to the data. Here, verbal feedback was provided and an overall agreement was reached. This process facilitated a discussion in which the 'transparency and coherence' of the analysis was examined in connection to the clarity of theme development in connection to the data and literature (Yardley, 2000).

The assumptions in terms of the quality checks were different to the IPA study. Template analysis is a flexible method and can be used from several different positions including a positivist position (King & Brooks, 2017). Therefore, the underpinning assumptions as part of this study related more to an inter-reliability check.

Reflexivity, the Mixed and Multi-methods Study. Reflexivity as part of the mixed and multi-methods study focused upon a second-level reflexivity in connection to the study design process. Reflexivity can be considered on two levels to transparently reflect the rich process of creating research (Patnaik, 2013). The first level (a mono-method approach) is where researchers explore their values, attitudes, motivations for the study design, the underlying assumptions, and personal factors such as gender and sociocultural influences (Frost, 2011). This allows a direct inquiry as to how the individual influences their qualitative research (Patnaik, 2013). The second-level refers to the integration of methods and how the researcher engages with the contradictions, tensions, or complementary factors associated with the methods (Frost, 2011). This second-level reflexivity was achieved through

developing a reflexive synthesis when considering the methods and how to resolve conflicting elements of the approaches (Marks, 2006). This reflexive synthesis is presented throughout Chapter five in note format to provide insight into the research design process and a commentary across the process (Frost, 2011). Reflexivity as part of the study design has also been considered to transparently reflect the rich process of creating novel research designs and it is hoped that it contributes to the credibility of the approach.

Conclusion

Chapter one presents an overview of the topic of the early diagnosis of cancer, cancer incidence, UK policy, NICE guidelines, current campaigns, the potential impact of the COVID-19 pandemic; historical approaches to healthcare utilization research, the concept of delay, more contemporary approaches, and the overall aims of the thesis. Chapter two presents the overall methodological approach to the thesis, the rationale of the design in connection to the phenomena, the different epistemologies of the work, and what quality criteria have been drawn upon to increase the quality of the studies presented in this thesis. Chapter one therefore, gives insight to the topic, although it should be noted that it is not a comprehensive review of the literature. Therefore, Chapter three will present a scoping review that examines:

- How lay referral has been conceptualised across the literature and
- How lay referral has been associated with or influences help-seeking behaviour and attendance at primary care following the recognition of bodily changes or illness symptoms.

In consequence, it is anticipated that the scoping review will give a more in-depth exploration of the literature in terms of time frame (the appraisal and help-seeking interval). The review will take more of a specific focus in connection to lay referral and potential help-seeking processes following the recognition of bodily changes or potentially cancer related illness symptoms. The scoping review will also enable the exploration of what current gaps exist in the literature.

Chapter Three

A psychosocial exploration of lay referral and help-seeking behaviour following the recognition of bodily changes and illness symptoms: a scoping review, concept map and thematic analysis

Introduction

The time frame in which people recognise a bodily change as an illness symptom and seek professional healthcare advice is the topic of discussion in Chapter one. Therefore, in order to build upon this, the below will focus on several specific aspects of the time frame. This will include a more in-depth discussion around traditional approaches to symptom recognition and lay referral.

Symptom Recognition and Help-seeking: A Traditional Psychological Perspective

Research grounded in health psychology is generally but not exclusively theoretically situated at a micro-level (an exploration of individual people or small groups), and thus has predominantly examined the influence of individual differences in terms of cognition, emotion, and personality upon 'delay', appraisal and help-seeking behaviour (Leventhal et al., 2016). Research from this domain suggests that people differ in how they individually perceive, respond to, and/or complain about body sensations (for example, Cameron & Leventhal, 2003). These individual differences can be theoretically exemplified by the self-regulation model: the 'common-sense model of illness' (CSM) (Leventhal et al., 1992) which provides a framework in which to explore and potentially understand how the interactive processes where people may recognise a bodily change as a health threat, experience emotional/ affective responses, develop perceptions of the threat and maybe plan to address or treat the health threat. These interactive processes are proposed as part of CSM to be part of a continuous feedback system in which people monitor the health threat and how the threat progresses (Leventhal et al., 2016). CSM has undergone 50 years of theoretical and empirical development in the field of health psychology and offers an alternative model and perspective to the Andersen et al. (1995) model described above (and in more detail in Chapter one).

CSM therefore offers a framework to predict how or if people adhere to treatments and how people may manage different health threats (Leventhal et al., 1992; 1996; 2016). The focus of CSM is on people's illness beliefs/ representations, emotional representations, and a range of coping responses as well as appraisal not only healthcare seeking or utilization. The CSM proposes that the understanding of

illness is formed through people's previous experience (personal or through observation of others or through diagnoses) and knowledge of illness gained in the social context (mass media, or other environmental cues). An individual's knowledge and experience of illness is applied to a bodily sign or change and linked to a pre-existing cognitive schema or 'illness schematics' (e.g. perceptions of what 'flu' is; 'what cancer is') stored within memory. If the bodily sign/change 'fits' a pre-existing schema of any specific illness symptoms then the individual will likely generate further perceptions, referred to in the CSM as 'illness representations' which comprise of beliefs about identity, timeline, cause, consequence, personal control, treatment control, illness coherence, and emotional representations. The cognitions are processed in a dual-parallel processing system that incorporates both the subjective cognitive illness representations and the emotional responses to those illness representations and the objective symptomatology, thus activating coping responses which may or may not include help-seeking or as a coping response (Leventhal et al., 2016).

Previous literature that has examined illness beliefs has included research that has explored breast cancer (i.e., Moon et al., 2019) and the relationship between illness beliefs, treatment, and depression outcomes (Lynch et al., 2011; 2015). For example, Dempster et al., (2015) outlined how there is a body of literature that explores CSM in connection to people's emotions and distress outcomes when they experience physical illness. Dempster et al. (2015) therefore, conducted a systematic review to examine the role of coping with a focus upon outcomes associated with quality of life, anxiety, and depression. The review included 31 articles with the results indicating that the domains linked with the perceived consequence, and emotional representations presented the strongest relationship with the outcomes the study reviewed. The authors suggested that coping variables (measured through scales such as the Brief COPE/ COPE such as problem-focussed, emotion-focused, and avoidant coping amongst others) were stronger predictors in terms of the outcomes than illness perceptions although there was no consistency in reference to how coping variables mediated the outcomes. Dempster et al. (2015) concluded that whilst illness beliefs are important, so is how people cope in relation to their experience of stress/ distress when people encounter physical illness and that theoretical clarification is needed in the context of coping variables. This highlights that CSM may not account for people's differing coping

responses outside what has already been conceptualised in the model and that measures in terms of coping (Brief COPE) used in conjunction with CSM may also face these issues. For instance, people may cope or draw upon other resources in response to their bodily changes that cannot be captured through the use of these quantitative measures as they do not allow for exploration of other coping variables beyond the concepts, they already encompass within the measures themselves. However, one suggested area that CSM includes in connection to coping is people's lay referral networks and how lay referral can influence how people respond to their bodily changes or illness symptoms (Martin et al., 2003). Lay referral will now be discussed below (Freidson, 1970) (see Chapter one for more information).

Lay Referral and Help-seeking: Traditional Sociological Approaches

Traditional medical sociology research focussing on lay referral systems relates to advice-seeking/ advice giving which was thought to organise the direction of people's behaviour by one referral to another. The traditional concept of lay referral systems was further defined by Freidson (1970) to include:

- People's culture and knowledge they have about health
- The interrelationship between the person and the lay referent

It was also proposed that people's lay referral systems hold cultural content in terms of ethic and/ or socioeconomic factors. This positioned lay referral as part of a system in which individual differences and factors were not relevant (Freidson, 1970). For example, as part of Freidson's book called 'Profession of medicine, a study of the sociology of applied knowledge; Freidson (1970) theoretically outlined 'rates of utilization in certain sample populations' as the main dependant variable and considered the social process of people 'becoming ill' as the independent variables associated with the content/ structure of the sample populations lay social context. The aim was to predict the utilization of services at a population level. In addition, Freidson (1970) further developed a theoretical lay referral system typology which incorporated the findings of the research by Raphael (1964) and Suchman (1964) (as cited in Freidson, 1970) who had explored how variations of lay referral systems related to ethnic patterns.

Another area in which lay referral has evolved is how lay referral has been contextualised by Martin et al. (2003) at more of an individual level in conjunction to CSM. For instance, Martin et al., (2003) discuss how lay referral can provide an opportunity for social comparison, evaluation, to help make sense of the experience, how exposure to other people may prime symptom perception, and how other people's illness behaviour may shape symptom perception. This demonstrates an alternative way to consider lay referral from more of an individual level as opposed to at a societal level. Scott et al., (2013) also acknowledged the role of social context and how people may self-regulate through their social interactions with other people when they experience illness symptoms. Scott et al., (2013) drew upon Social Cognitive Theory (SCT) in order to theoretically explain these social processes which included concepts such as the role of social sanctioning, social modelling, social persuasion, and vicarious learning (as discussed in detail in Chapter one). This exemplifying how lay referral has evolved in the literature although it must be noted that the majority of development in terms of lay referral would appear to have been theoretical.

Despite the majority of development appearing to be theoretical, the below review did not employ a theoretical or conceptually focused methodology (i.e., a theoretical oriented systematic review). There are several reasons for this as outlined below:

- Although there has been methodological advancement in the field in relation to theoretical reviews, they can present with methodological issues
- Methodological issues may relate to traditional literature reviews which rely on the researcher's knowledge
- Reviews may be constrained to the researcher's discipline or the researcher's particular perspective. This could result in a limited review of existing theory and a lack of exploration
- Theoretical systematic reviews are different from reviews of the empirical literature. They differ in reference to the goal of the review itself with theoretical systematic reviews aiming to 'open' the reviewers' thoughts in terms of the research/ potential hypothesis and empirical reviews relating to minimising bias as part of the review process (Campbell et al., 2014).

This review instead employed a scoping review methodology in order to broadly explore cross-disciplinary gaps in the existing literature but also to include all types of evidence (theoretical, conceptual, and empirical) in connection to the topic.

The Scoping Review, Topical Focus and Disciplinary Position

This scoping review will draw from published literature from the fields of health, public health, nursing, general practice, behavioural medicine, psychology, social psychology, health psychology, sociology, medical sociology, and anthropology, to enable a fuller understanding of the existing evidence (theoretical, conceptual and empirical) regarding the time frame between the detection of bodily changes and/or symptom recognition, lay referral and healthcare consultation. This time frame is otherwise referred to as the appraisal interval and the help-seeking interval as described by the Model of Pathways to Treatment (Scott et al., 2013) (figure 3.2). The review will take a broad focus upon this specific stage of the overall time frame to ensure an in-depth scope of the literature and will further provide an opportunity to consider the commonalities and/or differences in research findings offered by the different fields.

To build upon a range of previous cancer, pathway, and time frame research (i.e. Andersen et al., 1995 and Scott et al., 2013 as discussed in Chapter one) this review does not address all hypothesised stages of the models discussed above but instead, takes more of a specific focus. This specific focus relates to the potential influence of lay referral upon the time frame between symptom recognition and help-seeking behaviour in the context of healthcare consultation. This review aims to examine research that explored classically known cancer symptoms (breast lumps, neck lumps, unexplained bleeding, etc.) as well as other more generic bodily signs and/or changes, each of which may elicit a range of behaviours. From a social and health psychology perspective, the main difference between bodily signs or changes and illness symptoms is that illness symptoms are grounded within the individual's recognition and interpretation of these as being illness symptoms i.e., appraisals as described earlier (Leventhal et al., 1992; Radley, 1994).

Research Questions

A Preliminary Search

As part of the scoping review process the development of the research questions was iterative. For instance, a broad generic research question was developed in order to conduct a preliminary search. The research question related to the preliminary search was:

- How does lay referral influence professional healthcare seeking behaviour?

The preliminary search used the following broad topical key terms which later supported the refinement of the research questions: lay referral, lay referral network, lay networks, and lay referral system. Other key terms included review, systematic review, scoping review to narrow the search. The following databases were encompassed: PsycINFO, Web of Science, and the Cochrane Library, accessed online through the Bangor University online library and archives service or directly with Cochrane online. No evidence was found to suggest that a scoping review or systematic review addressing questions similar in focus to this review had previously been published.

Refined Research Question(s). The objective of this scoping review was to systematically explore the current extent, range, and nature of research activity regarding the following research questions.

1. How has lay referral been conceptualised in the literature?
2. How does lay referral associate with /influence help-seeking behaviour and attendance at primary care following the recognition of bodily changes or illness symptoms?

Research question one was intentionally designed to be broad leading to research question two which was developed within the specific context of the current inquiry. The primary research question sought to map how lay referral has previously been conceptualised in the literature (i.e., health, sociology, psychology etc.) and the sub-question then delved into what is known from the existing empirical literature about how lay referral is associated with and/ or influences help-seeking behaviour and

attendance at primary care following the recognition of bodily changes or illness symptoms.

Method

Why a Scoping Review?

The rationale for selecting a scoping review methodology as opposed to a full systematic review was based upon several different factors. The primary factor is related to how the different review methodologies influence the development of different types of research question(s). For example, systematic reviews aim to answer a specific or distinct set of research questions that are typically narrowed and refined, leading to, or in parallel with, the consideration of the review studies' eligibility criteria (Higgins et al., 2019). Eligibility criteria refer to the inclusion and exclusion criteria, or in other words, the focused attributes that a study must contain to be included or excluded as part of the overall review process. The eligibility criteria may encompass certain methodological designs, particular sample populations, focused theoretical approaches, and specific dates of publication. In order to support the decision making process in connection to these attributes, they are generally considered within a population, intervention, comparator, and outcome framework, otherwise known as PICO (amongst other frameworks) (Cochrane Training, 2021). This is different from a scoping review in which the approach to the research questions takes a broad position which enables the inclusion of multiple and varied study designs and methods without prescriptive predefined exclusion criteria (Arksey & O'Malley, 2005). Therefore, the use of inclusion and exclusion criteria is also different when using scoping reviews, with scoping reviews taking more of an iterative position in which the exclusion criteria are developed as part of the review process itself. This iterative aspect of scoping reviews is seen as an advantage when conducting a review that spans across the decades and different disciplines as the quality of literature may differ. Therefore, pre-defined exclusion criteria and the assessment of quality were not considered compulsory although a quality assessment has taken place. Hence, when considering what review method was suitable for the current study objectives, the researcher questioned if a systematic review would facilitate the development of a broad and multifaceted research question(s); or if it would allow for a wide enough eligibility (inclusion/exclusion)

when a large body of research across many decades and different disciplines needs to be reviewed. Consequently, a scoping review was used in order to explore the gaps in evidence (Peters et al., 2020).

The Scoping Review Framework. The Joanna Briggs Institute Manual was the scoping review framework chosen to inform this review, which also incorporates the work of Peters et al., (2020). The framework offers a comprehensive guide for researchers when conducting scoping reviews (the JBI Manual also offers other review guidance as well). The below table (table 3.1) presents the different stages outlined in the JBI Manual which were drawn upon as part of this review.

Table 3.1

Stages of The Scoping Review

| Stages | Details of the Stages |
|-------------|---|
| Stage one | Defining and aligning the objective/s and question/s |
| Stage two | Developing and aligning the inclusion criteria with the objective/s and question/s and balancing feasibility with breath/comprehensiveness |
| Stage three | Describing the planned iterative approach to evidence searching, selection, data extraction, and presentation of the evidence |
| Stage four | Conducting the search/ searching for the evidence |
| Stage five | Selecting the evidence |
| Stage six * | Extracting the data, collating, summarising and reporting the Results and charting the data |
| Stage seven | Analysis of the evidence (Incorporating a concept map for research question one, a numerical summary and a qualitative thematic analysis of the empirical key findings for research question two) |

| Stages | Details of the Stages |
|-------------|---|
| Stage eight | Presentation of the results |
| Stage nine | Summarizing the evidence in relation to the purpose of the review, making conclusions and noting any implications of the findings |

Note. *Consultation is optional, stakeholders were not consulted. However, throughout the development of the protocol, review, planning surrounding dissemination, the expert supervisory team was consulted.

Stage One: Defining and Aligning the Review and Research Questions

To develop the research questions as part of this scoping review, the Population, Concept, and Context (PCC) mnemonic was chosen as advised by Peters et al. (2020). This mnemonic, described in full in stage 2, provided a guide to develop two meaningful research questions. The refined research questions (following the primary search and as outlined above) enabled a richer examination of the literature. The development of the research questions was an ongoing process whereby the research team continuously clarified and refined the research questions in terms of the purpose and objectives of the review itself. This iterative process later guided the direction of specific inclusion criteria that was developed as part of an ongoing process as the review took place. This increased the effectiveness of the literature database search (Peters et al., 2020).

Stage Two: Developing the Review

Scoping Review Inclusion Criteria

The inclusion criteria comprised the Population, Concept, and Context (PCC), format as outlined by the Peters et al. (2020) guidance for scoping reviews and provided a broader and more inclusive ‘scope’ than that produced by other formats, such as PICO (Population, Intervention, Comparator, and Outcome) used in systematic reviews (Higgins et al., 2019). The specific development of what

constituted inclusion criteria was guided by the PCC. The PCC was accessed and re-accessed to examine the feasibility as part of a PhD project in terms of depth and breadth of the scope in alignment with the objectives and research questions (Peters et al., 2020).

The Population, Concept and Context

Population (research question one and two)

Broad inclusion criteria for the sample population and types of participants included were applied. The inclusion criteria also addressed sample populations of/from: all genders; different age groups from eighteen years of age across the adult life span; from many geographic locations; participants who had experienced bodily signs or changes and/or medically diagnosed physical illness symptoms that may or may not be cancerous and who had consented to participate within health, public health, nursing, general practice, behavioural medicine, psychological, psychosocial, sociological, medical sociology and medical anthropology research studies.

Concept (research question one and two). The ‘concept’ (in this case the phenomena of interest) in the context of this review was lay referral. The concept of lay referral was not exclusively grounded within the historical theoretical medical sociology tradition, and given the iterative nature of scoping reviews, evolved during the review process, informed by existing research, empirical literature, theoretical/conceptual papers, and book chapters (Peters et al., 2020).

Context (research question one and two). The ‘context’ referred to the broad time frame in which lay referral and help-seeking behaviour may occur following the recognition of bodily changes or illness symptoms and was examined across multiple different disciplinary contexts using a range of designs. This holistic approach facilitated the exploration of different conceptual understandings within different disciplinary contexts, varying methodologies, and a broad spectrum of research findings that provided an opportunity to identify potential gaps in the existing knowledge (Arksey & O’Malley, 2005; Peters., 2020). The review included theoretical, conceptual, and empirical literature which aimed to capture a spectrum of evidence.

Types of Sources (research question one and two)

The types of sources included any existing scientific literature including empirical research, qualitative research, quantitative research, mixed-methods studies, secondary data research, systematic reviews, meta-analyses, reviews of the literature, book chapters, conceptual papers, and theoretical papers. PhD theses, reports, policy, online healthcare information, NHS website information, and the grey literature were also included. In addition, all of the literature sourced was written in the English language due to the time scale and funding implications for translation (Arksey & O'Malley, 2005).

There was no quality assessment or rating as part of the review's inclusion criteria and all relevant research was included in this study regardless of quality/ reporting standards in accordance with the PCC and research questions. The quality of research was questionable; therefore, this enabled an inclusive approach to gain a full picture of the evidence, regardless of its quality. However, a quality assessment of the included empirical literature was conducted and reported as part of the review (table 3.9) that employed the Mixed Methods Appraisal Tool (Pluye et al., 2009; MMAT; 2018). The MMAT provided an opportunity to assess the quality of the literature based upon a checklist that enabled the appraisal of quantitative, qualitative, and mixed methods research. The ability to assess a range of methods and methodologies was paramount as part of this review given the broad cross-disciplinary scope.

Scoping Review Exclusion Criteria (research question one and two)

The exclusion criteria included studies that purposely sampled groups or populations under the age of 18 years of age as the focus of this thesis is in reference to an adult sample population. The exclusion criteria also included literature that explored lay referral with regards to a different area or context (i.e., mental health, disability, caregiving, dementia, sexuality, chronic pain, palliative care, psychotherapy, linguistics, organisational, economics, philosophy, and digital health research studies) as opposed to focussing on lay referral in the context of physical bodily changes /physical illness symptoms. The rationale for this was to ensure that the literature included in the review related to physical health (i.e., bodily signs/ changes and/ or symptoms that may or may not be cancerous illness symptoms).

Search Strategy and Building Search Terms

Three main steps were taken to build the search strategy (detailed below) which ensured a comprehensive approach to both published/unpublished studies and grey literature suited to the purposely broad review questions. One overall broad search strategy was appropriate to address both research questions. This enabled a broad scope across various disciplines, which may or may not use different methods.

Building the Search Terms; Mapping of the Redefined Research Questions, the PCC and Initial Search

Table 3.2 demonstrates how the research questions were initially mapped in terms of the keywords sourced from the literature and how each of the components of the above PCC were relevant. The main component of the PCC for research question one was the concept i.e., lay referral, whereas the main components of the PCC for research question two were the concepts of bodily changes, illness symptoms, lay referral, help-seeking, and attendance at primary care. Following this, the keywords were further developed through an analysis of the text words contained in the title and abstract of retrieved papers and index terms of the initial limited database search (Peters et al., 2020). This initial limited search included two online databases (Social Sciences Premium Collection and PsycINFO) as suggested by JBI Manual. This keyword analysis involved the exploration of alternative words, synonyms, different terminology, word plurals, different word forms, spellings, and common versus specific terms in regards to all of the concepts.

Table 3.2*Mapping Research Question One and Two*

| PCC | | Terms | Keywords |
|--------------|--|-----------------------------------|-------------------------------|
| | | (Participants, Concepts, Context) | (Derived from the Literature) |
| Participants | Adults | | N/A |
| Concept | Bodily changes, illness symptoms | | Bodily changes |
| | | | Bodily signs |
| | | | Illness symptoms |
| | | | Symptoms |
| | | | Illness |
| | Lay referral | | Lay referral |
| | | | Lay referral patterns |
| | | | Lay referral network |
| | | | Lay network |
| | | | Lay referral system |
| | | | Lay referral role |
| | Help-seeking, attendance at primary care | | Help-seeking behaviour |
| | | | Professional help-seeking |
| | | | Medical consultation |

| | | |
|---------|-----|--|
| | | Consultation with a health care professional |
| | | Decision to seek medical assistance |
| | | Illness behaviour |
| Context | N/A | N/A |

Table 3.3

The Developed Mapping of Research Question One and Two

| PCC | Term | Key Words |
|--------------|----------------------------------|---|
| Participants | Adults | N/A |
| Concept | Bodily changes, illness symptoms | Bodily changes Bodily signs Bodily disturbances Bodily sensations Bodily feelings Bodily experience Bodily complaints Physical Illness symptoms Illness Symptoms |

| PCC | Term | Key Words |
|-----|--------------|---------------------------|
| | | Symptom of disease |
| | | Symptom recognition |
| | | Perception of symptoms |
| | | Sickness |
| | Lay referral | Lay referral |
| | | Lay referral patterns |
| | | Lay referral strategies |
| | | Lay referral network |
| | | Lay networks |
| | | Lay referral system |
| | | Lay referral role |
| | | Lay referral mechanisms |
| | | Informal networks of care |
| | | Social networks |
| | | Lay consultation |
| | | Lay advice seeking |
| | | Help-seeking behaviour |

| PCC | Term | Key Words |
|---------|--|---|
| | Help-seeking, attendance at primary care | Professional help-seeking Healthcare consultation Health care utilization Primary care help-seeking Help-seeking in primary care Medical consultation Consultation with a health care professional Decision to seek medical assistance |
| Context | N/A | N/A |

Building the Search Strategy and Search terms for RQ2

To build upon the above terms and keywords several tools were used to create a search strategy (as listed in Table 3.4). These tools were: Boolean operators that join keywords ('AND', 'OR', 'NOT'); and Truncation (*) which is a tool that enables different variations of the same word to be searched. During the development of the search strategy, the reviewer gained expert support, advice, and input from a university librarian and supervisory team.

Table 3.4*Search Terms*

| Number | Search Terms |
|--------|---------------------------|
| 1 | Lay referral |
| 2 | Lay referral system* |
| 3 | Lay referral network* |
| 4 | Lay referral role* |
| 5 | Lay consultan* |
| 6 | Social network* |
| 7 | OR / 1- 6 |
| 8 | Bodily change* |
| 9 | Bodily sign* |
| 10 | Physical symptom* |
| 11 | Physical illness symptom* |
| 12 | Symptom recognition |
| 13 | Symptom* appraisal |
| 14 | OR / 8- 13 |
| 15 | Help seeking behavior* |
| 16 | Health care utilization |
| 17 | Primary care help-seeking |
| 18 | Medical consultation* |

| | |
|----|---------------------------|
| 19 | Healthcare consultation* |
| 20 | OR / 15- 19 |
| 21 | 7 AND 14 AND 20 |
| 22 | AB (7 AND 14) AND TI (20) |

Search Strategy Step Two for Both Research Questions (RQs)

A second main database-specific search was conducted across the following four online databases: Pubmed, Social Sciences Premium Collection, PsycINFO, and Web of Science. This built upon the scoping review protocol and all of the identified keywords, index terms, and developed search terms were utilised in the search (as outlined above).

Search Strategy Step Three for Both RQs

The final third step of the search strategy involved a review of the reference lists in regards to all of the identified literature that was selected for inclusion as part of the scoping review. Here, each reference list was examined for additional sources relevant to the research questions. A lateral search of the grey literature was also conducted to gather unpublished and/or difficult to locate sources please see the below. All of the literature gained through step two and three were transferred, organised, and stored in REFworks software. In addition to the above, a search of the grey literature was conducted and encompassed the sources below (see table 3.5). This search was conducted to capture any relevant unpublished or non-commercial publications. These sources included: a general online search of the key terms, a search of the grey literature, a search of public online health-related sources, previous doctoral research, and extensive hand searches.

Table 3.5*Grey Literature Search and Sources*

| Type of Source | Data Sources |
|---------------------------------|---|
| General searches (key terms) | Google scholar |
| Unpublished and Grey literature | <p>OpenGrey is a (European grey literature repository)</p> <p>The National Institutes for Health</p> <p>Health related websites:</p> <ul style="list-style-type: none"> • NICE • NIHR • Department of Health • NHS Direct |
| PhD Thesis and dissertations | EThOS; Open Access Theses and Dissertations |
| Hand Searches | Reference list checking of included studies |

Stage Three: Developing the Iterative Approach to the Search

Study selection and PRISMA screening (see figure 3.1) (PRISMA screening presents a visual summary and diagram of the scoping review screening process) was based upon six steps, the first of which was to identify the number of records gained through the database searches. The second step identified and documented the number of records gathered through other lateral searches (described above).

The third step was de-duplication i.e., the removal of records which were duplicated across or within different databases. At step four, the remaining records were screened by title and abstract. If the title and abstract did not meet the inclusion criteria then these records were excluded by the principal researcher (reviewer one). Step five of the screening process concerned the assessment of the remaining included records and the book chapters, with all assessed for study eligibility. Those that did not meet the inclusion criteria were then excluded. Each of the full-text articles were dual reviewed (EC, BO) with 100% agreement in terms of the general eligibility and study inclusion. The final step involved documenting the quantity of included records and grouping the records by type of evidence (i.e., types categorised by empirical papers, theoretical papers, book chapters etc.). The overall selection process was conducted per the PCC and iterative inclusion criteria as outlined in the scoping review protocol were applied in discussion with the researcher's supervisory team.

Data Extraction, Charting and Risk of Bias

The extraction and charting process enabled the researcher to descriptively summarize the findings of the included studies and to document information relevant to the current research questions. The forms were piloted using five papers and subsequently re-developed to include an additional section for researcher's notes and amend the order in which the sections were presented. Below is an example of the data extraction form that was developed (see table 3.6). All of the data extracted was charted and documented using a paper format in the initial stages (as outlined in the below example) and was developed as part of the iterative review process to ensure that any additional information relevant to the scoping review was captured, stored, and recorded (Arksey & O'Malley, 2005; Armstrong et al., 2011). The charted data (20% of the included studies) generated by reviewer one was independently checked for accuracy by the second reviewer (EC, BO).

Table 3.6*Data Extraction and Charting Form*

Points for Data Extraction

Discipline or field of study

Author(s)

Year of publication

Theoretical position

Source of evidence

Method

Aims / purpose

Study population / age 18 +

Sample size

Analysis

Key findings

Researcher notes

Stage Four: Conducting the Search

Data extraction and charting of the data required the researcher to create a logical and descriptive overview of the included studies which aligned with the RQs. Key information was extracted from the individual sources included in the review (as outlined above in the charting form). This included the extraction of data from several different disciplines, which employed a range of methods, and samples which was labour intense. Data extracted was carefully recorded and charted in the table of

results (table 3.7; 3.11; 3.12; 3.13). The charted table of results was updated as part of an iterative process (Peters et al., 2020), and organised according to the most recent publication within the following three main categories:

- Empirical literature (quantitative, qualitative and, mixed-methods)
- Theoretical/conceptual papers and
- Book chapters

As part of data extraction, the author's names; source of evidence; discipline/ field; theoretical position; methods; aim; study sample and size; key findings and relevant comments were noted by the researcher for the both empirical and theoretical literature (tables 3.7; 3.10; 3.11; 3.12). Data extracted from the book chapters was also labour intense, with the researcher examining the chapters and that data charted in a separate table as the content of the chapters differed between each source and required a more in-depth extraction in comparison to the empirical and conceptual literature (table 3.13).

Analysis and Presentation of the Evidence - RQ One

A Concept Map

Concepts maps of theory present a visual diagram, in this case, the data gathered and mapped in connection to RQ one '*how has lay referral been conceptualised in the literature?*'. The design of the concept maps of theory was based upon methodological guidance outlined by Maxwell (2005) that presents a tool to clarify theory (as opposed to a concept mapping to create a conceptual framework). The concept map of theory was developed initially in a paper draft format and then transferred to an electronic word package. The concept map of theory was developed in two main stages with considerable re-formulation and development across the different disciplines and time (decades). This required the researcher to invest much time into the familiarisation of the data extracted, the topic, how the lay referral had evolved in accordance with the scoping review findings, and how these factors interrelated.

- The first stage involved the creation of a timeline (in decades) and then the different conceptualisations of lay referral in relation to the different disciplines across the created timeline were plotted (see figure 3.2). A variation of text boxes, text circles, and arrows were used to visually express different aspects and relationships across the concept map.
- The second stage of the concept map examined different relationships between these conceptualisations. A number of areas were carefully considered in isolation and collectively (or at a more overall global level). This included the identification of where, when and how the theoretical, conceptual, and disciplinary connections sat within and across the map. The differences and contradictions between these factors were also noted. Contextual factors were also considered to situated the different aspect of the concept map of theory. This was important to capture the complexity of both the task and the how the key findings were brought together. The information generated throughout this process presented the evidence and results for RQ 1 (Maxwell, 2005).

The results of RQ 1 are considered in isolation and have been presented in this chapter separately to the presentation of evidence in connection to RQ 2. This is because RQ 1 and RQ 2 aimed to explore different aspects of the same topic in terms of the time frame and lay referral as part of this review. This highlighting how differing methods produce different knowledge, equally both as important as each other.

Analysis and Presentation of the Evidence - RQ Two

The Use of Thematic Analysis as Part of the Empirical Key Findings Analysis

When conducting the scoping review considerations around the method of analysis was considered. This included the consideration of a standard discussion of the review results in comparison to a thematic analysis of the key findings. A thematic analysis was chosen to thematically describe themes generated through the scoping review empirical key findings. Thematic analysis was chosen because it is a cluster of methods that are theoretically flexible and can be used differently to

explore patterns and meanings within different forms of data (Braun & Clarke, 2006; 2013). Thematic analysis can take several positions, such as an inductive approach (i.e. constructionist) or a deductive approach (from a more realist or positivist position) amongst others. When employing an inductive approach, the analysis is not usually influenced by existing theory, whereas, a deductive approach is guided by pre-existing concepts, and theory related to the topic (Braun & Clarke, 2013). Therefore, an inductive thematic analysis, at a semantic level that aims to reflect the explicit context and content of the empirical key findings gathered through the scoping review was conducted. Here, the epistemological position took a realist approach which assumes that reality is evident within the data (Braun & Clarke, 2020). This approach was selected in order to gain a thematic understanding of existing empirical literature across the different disciplines which may draw upon differing methods. The results of the thematic analysis are discussed as part of the overall scoping review findings.

A Thematic Analysis of the Results. A thematic analysis of the charted data and the extracted key findings was conducted to generate the results as part of RQ 2:

‘What is known from the existing empirical literature about how lay referral is associated with and/ or influences help-seeking behaviour and attendance at primary care following the recognition of bodily changes or illness symptoms?’.

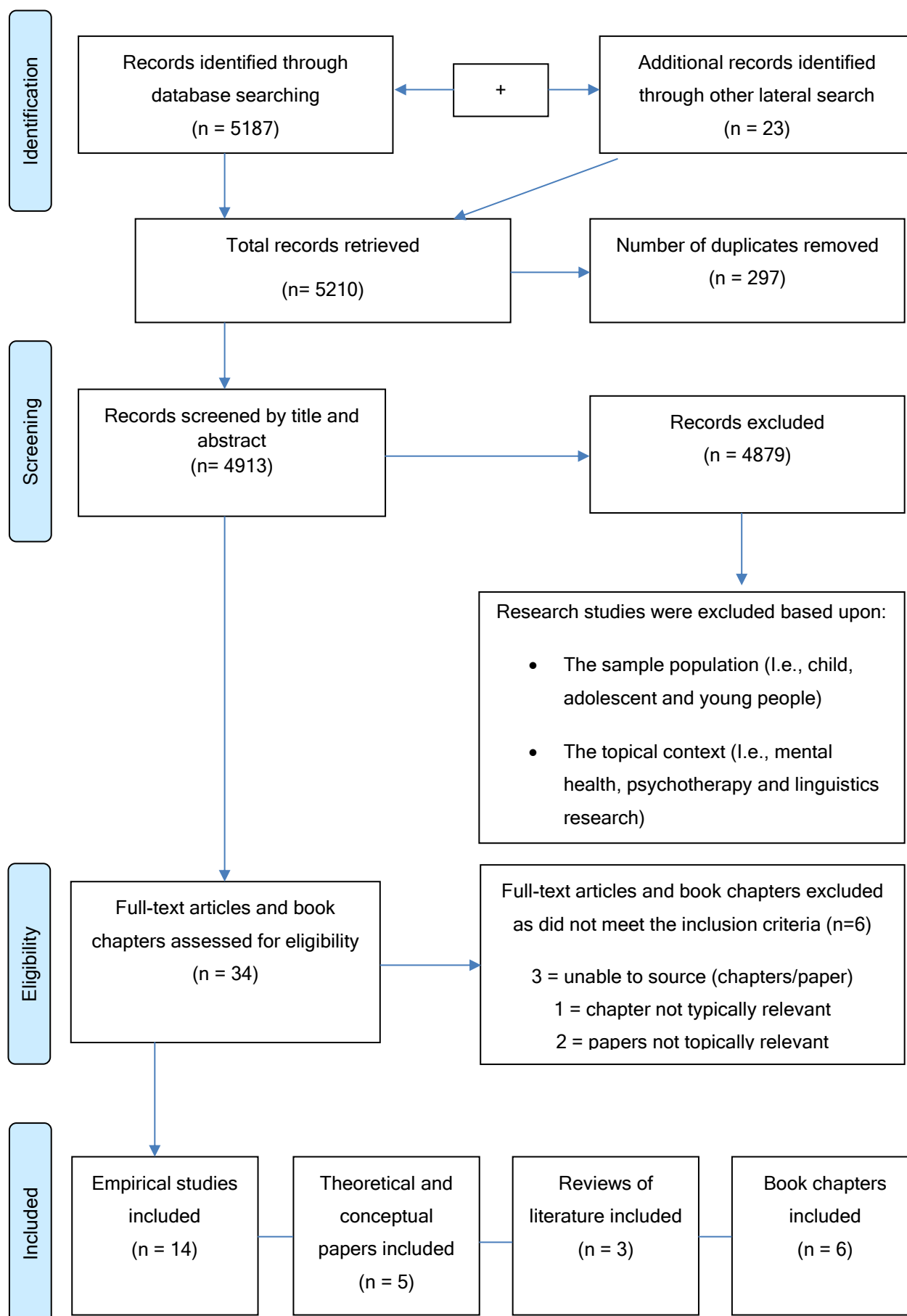
The charted data and extracted key findings from the empirical research (as opposed to book chapters, conceptual/ theoretical papers, and literature reviews which had also informed RQ 1 were subject to the thematic analysis. The following phases were followed as part of the analytical process (Braun & Clarke, 2006) (appendix A):

- Familiarisation with the overall charted data/ extracted key findings and documentation of initial ideas
- The systematic generation of initial codes (i.e. interesting features across the entire data / collating data relevant to each code)

- Searching for themes (collated codes into potential themes, gathered all data relevant to each potential theme)
- Reviewing themes across two levels (checked themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generated a thematic 'map' of the analysis)
- Defining and naming themes (on going analysis refined the specifics of each theme, generated clear definitions names and map)
- Producing a findings section for the scoping review (final phase of analysis and related back to the research question/ the literature as part of the scoping review and reviewed with the supervisory team) (Braun & Clark, 2006).

Stage Five and Six: Selection of the Evidence and Results Section

The PRISMA flow chart below (see figure 3.1) presents the way in which the evidence was identified, included and excluded throughout the scoping review process. The flow diagram also outlines the reasons as to why some of the literature was excluded.

Figure 3.1*PRISMA flow chart*

Numerical Summary and Study Selection

The results of the scoping review electronic database search initially located 5187 records and 297 duplicates were removed. An additional 23 sources of data were gathered through a lateral (Google/ Google Scholar search) and a search of the grey literature conducted. A total of 4913 titles and abstracts were screened, with 4879 of these results excluded (see PRISMA, figure 3.1). Literature was excluded from the review based upon the population and the context in which the studies were situated. For instance, excluded research studies included projects that purposely sampled groups or populations under the age of 18 years of age (child, adolescent, and young people). Other studies were excluded based upon the context in which lay referral was empirically investigated that did not make reference to the time frame, physical bodily changes and/ or illness symptoms (i.e., mental health, palliative care, psychotherapy, and linguistics research). This was based upon the research topic but also in terms of feasibility as part of a PhD project (see figure 3.1 for exclusion criteria). The full texts of the remaining 34 sources (i.e., empirical research, theoretical/conceptual papers, and book chapters) were obtained. A further 6 became excluded upon full text examination due to a lack of topical relevance (e.g., related to emergency care) and accessibility (i.e., two sources were not accessible- a book from 1972 (author now deceased) and another source from 1984). The remaining 28 sources were included in this study (22 empirical/ theoretical and conceptual articles and 6 book chapters, charted separately, see below; each of the empirical papers have been allocated a numeric identifier, for author information see table 3.8). The findings addressed both research questions although the data extracted from the book chapters primarily supported research question one.

Table 3.7*Charted Data of the Empirical Studies and Results Table*

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|---------------------------|--|---|---|--|--|
| 1 | Empirical study | Nursing and Public Health | Qualitative Retrospective Cross-sectional Semi-structured interviews Thematic analysis | To explore the experiences of Ghanaian women diagnosed with advanced breast cancer (symptom recognition, appraisal and help-seeking behaviour). | Women diagnosed with advanced Stage III or Stage IV breast cancer. Female N= 11 Country: Ghana | Women delayed presentation for several reasons. Symptom appraisal occurred in two stages: individual understanding of breast symptoms (cognitive, social, psycho-cultural) and interactive understanding of the breast symptom. 5 themes were identified: symptom experience, knowledge of breast cancer, the role of social life, and network, coping with a breast symptom, and intent to seeking health care. A conceptual model was developed and outlined the key factors and concepts. | Women disclosed their bodily changes with significant others/ social networks (immediate family members, workmates, pastors). The opinion of others helped to understand, created meaning and how to manage their bodily changes. Others avoided talking about it outside of their trusted networks (stigma/ social rejection). Some women sought healthcare advice , others delayed based upon on advice about alternative therapies. |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|--|--|--|---|--|
| 2 | Empirical study | Health Research | Mixed methods Retrospective Cross- sectional Structured telephone interviews and a medical chart review | To investigate patients' symptom appraisal, help seeking, and lay consultancy up to the time they first went to see a health care professional (HCP) | A medical diagnosis of head and neck cancer (Symptomatic patients newly diagnosed with squamous cell carcinomas of the oral cavity, oropharynx, and larynx) Aged between 27 and 63 years N= 83 Both male (81) and female (2) | 18% of people reported that their symptoms needed further investigation. 6% attributed their symptoms to cancer. 89% reported a lack of awareness of the early warning signs/ symptoms of HNC. 57% discussed their symptoms with one lay consultant or more before gaining help from a healthcare professional. | 57% disclosed their symptoms to a lay consultant (spouse, parent, child, sibling, cousin, workmate, friend) prior to seeking medical help. Lay consultation encouraged 49% of the patients to seek medical help but did not influence 42% of the participants understanding of the situation. Spouses appeared to have a greater influence on participant's decisions to seek for help. The study suggested that men were less likely to consult when compared with women. |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|---|--|--|--|--|
| | | | | | Country: Ontario, Canada | | |
| 3 | Empirical study | Health research | Qualitative Retrospective Cross-sectional Semi-structured interviews Framework Analysis | To explore symptom appraisal and help-seeking among patients referred to specialist services with symptoms of colorectal cancer. | Patients referred with symptoms suggestive of colorectal cancer aged between 43 and 87 years N= 40 (18 participants subsequently diagnosed with CRC while 22 were not) 22 Male 17 Female | Several different factors influenced symptom appraisal and help seeking behaviour. For example (amongst others) psychosocial factors (e.g. knowledge, attitudes, beliefs, fear, etc.) Healthcare factors (e.g. relationships with GP, safety netting, access etc.) and social factors (e.g. the influence of significant others, social comparison, social norms, and family history). Findings suggest that people sometimes normalised their symptoms within their social environment and delayed seeking for healthcare advice. | Some of participants discussed their symptoms with others (partners, family, friends, workmates) however the study suggested that social comparison with regards to colorectal symptoms was limited because some of the symptoms were perceived as private/ embarrassing potentially due to sociocultural norms. Participants only sought healthcare advice when they could no longer manage their symptoms or when they were disruptive to their lives. |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|---|--|--|--|---|
| | | | | | Country: England | | |
| 4 | Empirical study | Health research | Mixed methods although the article focused on the qualitative data and did not include the quantitative | To explore the ways in which men account for the timing of a diagnosis of prostate cancer with a focus upon relational factors | Men diagnosed with prostate cancer Male sample N= 30 | Relationships, (spousal, familial, and friendships), appeared to be important as part of informing men's help-seeking behaviours and supported access to primary care. | Most men discussed their symptoms with their partners or friends with similar symptoms. These discussions were associated with increased help seeking in terms of healthcare professional advice. Some men delayed as they did not disclose their symptoms and self-managed thinking, they were emotionally protecting their loved ones. Those who had previously been diagnosed with prostate cancer, appeared to encourage other men to go for testing. |
| | | | Retrospective | and the role of relationships in | And | | |
| | | | Qualitative | terms of diagnosis | N= 19 of the male | | |
| | | | Cross-sectional | | participants | | |
| | | | Framework Analysis | | partners were also interviewed | | |
| | | | | | Glasgow, Scotland | | |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|---|--|---|--|---|
| 5 | Empirical study | Sociology | Qualitative Retrospective Cross-sectional In-depth interviews Analytical technique akin to grounded theory (not specified) | Draws on social network theory/ research to examine how networks influence collective experiences of racism and health-related behaviour | Gypsies and travellers N= 39 19 males 20 females Aged between 18 and 66 years Country: England | Data indicated that people's social networks influence health behaviour which is shaped by the social context in connection to wider social structures, thus making generalizations challenging. | Lay consultation was perceived as an alternative to healthcare systems. Participants spoke to spouses, elderly women, and friends when they experienced a health problem for information and advice. Social networks provided lay consultation and findings highlight how shared health beliefs/information, access and use of healthcare services is influenced in the social context which effect people seeking healthcare advice. |
| 6 | Empirical study | Public Health | Qualitative Retrospective Cross-sectional | To determine patterns of self-referral among Hong | Females who had sought advice for self-detected breast symptoms | Atypical/ painless symptoms were more common among women who delayed in presentation to their healthcare provider. Barriers | Some women spoke to other women about their breast symptoms. This was described as a 'social disclosure' which included |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|---|--|--|---|---|
| | | | Semi-structured interviews | Kong Chinese women with self-detected breast symptoms | Cantonese-speaking Females Aged 20-81 years N= 37 Country: Hong Kong | to healthcare included cost, access, time and embarrassment. | talk about discussions about symptoms/ Interpretation and comparison which prompted help-seeking. Help-seeking was encouraged if the women they spoke to had previous experience of cancer. Lay referral also included the participant's siblings, female relatives, adult children etc. |
| 7 | Empirical study | Health research | Quantitative Retrospective N= 1388 Cross-sectional Qualitative N= 35 | To examine age and contextually related factors that are influential in lay referral patterns during cardiac treatment decision making | Heart attack survivors Aged between 55 and 74 years Gender distribution discussed as | An association between older age and the reliance on others to seek medical attention for cardiac symptoms was found. Other findings indicated that gender shaped lay referral. | Findings indicated that people engaged with and consulted a wide range of people. Spouses/ children were reported to help the decision to seek advice, for older respondents, friends and other family members were also influential. |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|--|---|---|--|--|
| | | | Country-America | | part of the analysis | | 42.2% indicated that someone else made the decision re gaining healthcare seeking behaviour. 35.4% reported that their spouse made the decision and 20.4% their child (amongst others). The findings also highlight the importance of 'significant <u>others</u> ' and how personal characteristics (age, gender) also influenced the process. |
| 8 | Empirical study | General practice | Mixed methods Retrospective Cross-sectional Telephone interviews and a series of health status scales | To explore and to describe the importance (or otherwise) of conversations in the decision to consult for healthcare advice. | Those who consulted with new symptoms Quantitative study N= 1190 Qualitative | 70% reported that conversations were important in reference to their help-seeking behaviour. Partners were likely to influence people's decision to consult. No extended referral network was found. In terms of sex differences, men talked to the same number of women and men, but women talked to more women than men. | 126 (34.5%) conversations were reported with relatives other than partners, 68 (18.6%) with partners, 66 (18.1%) with workmates, 59 (16.2 %) with friends, 12 (3.3%) with neighbours, 18 (4.9%) with nurses, 9 (2.5%) with pharmacists, and 7 (1.9%) with others. No advice was given in 96 (26%) conversations. |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|-------------------------|--|--|--|--|
| | | | | To compare the importance of conversations with partners to conversations with non-partners and to investigate whether patients with a worse perceived health status are less likely to use lay referral networks than patients with a better perceived health status. | <p>N= 101</p> <p>76 females and 25 males</p> <p>Aged between 14 and 80 years</p> <p>Country: England</p> | Only a small variation was found between these discussions in terms of age, social class, and perceived health status. | Advice to see the doctor occurred most frequently in 210 (58%), 109 of which were considered of no importance in the decision to consult. Advice to take medicine was given in 74 (20.4%) conversations. In 21 (5.8%) conversations the advice was to see someone other than the doctor (9-pharmacist; 5 other health care professionals). |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|---------------------------|---|---|---|---|---|
| 9 | Empirical study | Aging and health research | Quantitative Retrospective Cross-sectional Symptom and self-care questionnaires collected through face-to-face methods | To investigate the question of the role of gender, living arrangements, and use of lay consultation in the use of self-care strategies. | Aged 65 years and over N= 608 Gender distribution was discussed as part of the analysis Country: America | This study suggested that female relatives are important in regards to advice but that neither gender nor living arrangements are closely related to the tendency to seek lay advice. | 55% reported that they spoke with a friend or relative. This varied pending the symptom. Wives, daughters, sisters were 2x more often consulted than male network members. For 36% of symptoms, the lay consultant provided no advice; 15% of advice was to adjust their activity, 14% to seek professional help and 12% offered sympathy or empathy. |
| 10 | Empirical study | Social science | Quantitative Retrospective Cross-sectional House hold survey | To determine whether males and females differ in the tendency to respond to their symptoms when self-treatment and lay consultation as | White, married individuals who lived in nuclear families and who had reported at least one symptom in the in a 4 week recall period | There was no statistical association between sex and behavioural response. 34.3% of males and 33.8% of females did not respond nor took action. 8.1% men and 7% of women spoke with lay consultants. 25.7% females sought medical care compared to 22.2% of men. 33.5% of males | Sex differences were most prevalent in terms of lay consultation although very few people of either gender engaged with lay consultation. Those of higher social class were more likely to use healthcare services whereas women of higher social class were more likely to engage with lay |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|--|--|--|---|---|
| | | | | well as medical care are considered | N= 532 284 females 248 males Country: America | treated themselves, 33.5% of women self-treated. The female: male relative risk for use of medical care during 4 weeks was 1.16 (95% confidence interval, 0.86, 1.58). | consultation. Women who reported greater symptom severity sought healthcare advice although women who worried about their symptoms sought lay consultation. |
| 11 | Empirical study | General practice | Mixed methods Prospective Longitudinal 6 weeks health diaries and in-depth interviews | To examine women's perceptions of illness and the effects of lay consultations and social networks on the use of general practitioner services | Female Sample N= 79 Aged 14-44 years Country: England | Large kinship networks appeared to influence the women's help-seeking and consultation with their general practitioners; whereas large friendship networks seemed to have the opposite effect. The authors attributed this to how the discussions of symptoms with kin may be intense and lead to kin referrals to general practitioners. This is opposed to discussions with friends which may be more | Women who were married reported that they consulted with their husband; with half of the women also consulting a female friend. Women who reported that they were single, separated or divorced indicated that they consulted with their mothers, then female friends. In accordance with the study findings the symptoms that the women had experienced had little influence upon who they consulted. Of the 547 lay consultations |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|--|---|---|---|---|
| | | | | | | casual and result in symptoms being redefined as unimportant and less in need of medical attention. Data gathered from the health diaries indicated that 71% of the 49 symptom episodes that precipitated medical consultations were discussed with a lay person before contact was made with a doctor. | recorded, 50% were with husbands, 25% with female friends, 10% with mothers, 8% with female relatives other than mothers, and 7% with various others (for example, fathers or boyfriends). |
| 12 | Empirical study | Family studies | Quantitative Retrospective Cross-sectional Statistical data gathered through interviews (type not outlined) | To examine the relationship between health utilization and some selected aspects of family and friend networks. | Household sample N= 191 (185 females and 6 males) Country: America | The findings indicated that the larger the friend networks, the more social interaction, which increased support and less delay in utilization of health services. The larger the family networks, the more interaction, and the more support was available, the longer the delay in utilization | This study took a social network approach and whilst differences between family networks and friend networks did not explain the variance in help-seeking behaviour, evidence suggested that these networks operate in opposite directions. For example, none of the participants reported an absence of networks, whilst 3% of the sample reported as few as one contact |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|---|--|--|---|--|
| | | | | | | | outside the household. At the opposite extreme, less than 4% reported four or more contacts among both family and friend relations. From this, it would seem that respondents tend to be towards being involved in either friend or family network which in turn influences their help seeking behaviour. |
| 13 | Empirical study | Sociology | Methods (type not outlined) Prospective Longitudinal Statistical data gathered through interviews (mainly reports the data | To examine the role of family, its kin and friendship networks in the use of health and welfare services | Working class sample with two sub samples (utilizing and underutilizing) N= 87 No gender distribution reported | Socioeconomic status/ length of city residence was statistically controlled for; differences were found between the utilizers and underutilizers. | The findings found that the underutilizers had more family living in the same house and, when controlled for, still had more family living close geographically. The utilizers visited family less than the underutilizers did and, when they did see the family, it was often at the relative's house, not their own. Utilizers often lived closer to friends. Both the utilizing group and the |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|--|--|---|--|---|
| | | | from the first interview) | | Scotland | | underutilizing group generally reported being employed, but the underutilizers did not report the tendency to have friends at work, whereas this was evident in the utilizers group. Utilizers use their friends and husbands and make less use of mothers or other relatives, and would tend to consult a narrower range of lay consultants. Underutilizers relied on a range of relatives and friends as lay consultants. |
| 14 | Empirical study | Sociology | Methods not clearly outlined (type) Quantitative Retrospective | Examined factors affecting the networks employed, their composition, the quality of ties that characterized the interaction within the networks, | Sample was those aged 45 years and over N= 800 Gender distributions | Findings build upon previous research in reference to lay referral systems and the personal influence of people's social networks. | Men were most likely to encounter a need for a health service they had not used before in the decade immediately after reaching the age of 45; the use of unfamiliar health services then seemed to decline as age increased. Women, resorted to new sources of healthcare fairly |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|-------------------------|---|--|--------------|--|
| | | | Cross-sectional | and the effect that such networks had on decisions reached. | reported in terms of differing analysis Country: America | | consistently throughout their middle and advanced years. Elderly women employed such services far more than most male participants. The amount of time it took to decide on a health service varied - 20% decided in less than two days; a few took a year or more; the majority (76%) took less than two months. The speed with which decisions were reached was positively correlated with the severity of the symptoms/condition. 45% of the personal contacts were with relatives: 26% were with their spouse; 17% with an adult daughter; 10% with an adult son; and 26% with other relatives. Friends and acquaintances account for another 27% of the contacts, while professional counsellors such |

| Number Identifier | Source of Evidence | Discipline / Field | Methodology and Methods | Aim | Sample Population, and Sample Size | Key Findings | Lay Referral as Discussed as Part of the Extracted Data |
|-------------------|--------------------|--------------------|-------------------------|-----|------------------------------------|--------------|---|
|-------------------|--------------------|--------------------|-------------------------|-----|------------------------------------|--------------|---|

as lawyers and ministers were rarely consulted. Moreover, women were likely to rely on relatives to a far greater extent than men. Although men frequently sought advice from their spouse, far more women sought information from acquaintances/ friends rather than from kinsmen.

The below table (table 3.8) presents the numerical identifier for each of the charted empirical articles, and the authors' name.

Table 3.8

Table of References for the Empirical Articles

| Numerical Identifier | Authors' Name and Date |
|-------------------------|---|
| 1 | Bonsu, A. B., & Ncama, B. P. (2019). |
| 2 | Queenan, J. A., E., Gottlieb. B. H., Feldman-Stewart, D., Hall, S.F., Irish, J., & Groome, P, A. (2017). |
| 3 | Hall, N., Birt, L., Banks, J., Emery, J., Mills, K., Johnson, M., Rubin, G. P., Hamilton, W., & Walter, F. M. (2015). |
| 4 | Forbat L, E., Place, M., Hubbard, G., Leung, H., & Kelly, D. (2013). |
| 5 | Smith, D., & Ruston, A. (2013). |
| 6 | Lam, W. W. T., Tsuchiya, M., Chan, M., Chan, S. W. W., Or, A., & Fielding, R. (2008). |
| 7 | Schoenberg, N. E., Amey, C. H., Stoller, E. P., & Muldoon, S. B. (2003). |

| Numerical | Authors' Name and Date |
|------------|--|
| Identifier | |
| 8 | Cornford, C. S., & Cornford, H. M. (1999). |
| 9 | Edwardson, S. R., Dean, K. J., & Brauer, D. J. (1995). |
| 10 | Meininger, J. C. (1986). |
| 11 | Scambler, A., Scambler, G., & Craig, D. (1981). |
| 12 | Salloway, J., & Dillon, P. (1973). |
| 13 | McKinlay, J. B. (1973). |
| 14 | Booth, A., & Babchuk, N. (1972). |

Table 3.9 describes a quality assessment of the empirical literature charted as part of the scoping review. The assessment of the literature was generated through the Mixed Methods Appraisal Tool (MMAT) (2018) (appendix B).

Table 3.9*Quality Assessment of the Empirical Literature*

| Charted Number | Results of the MMAT by a Star Descriptor | Charted Number | Results of the MMAT by a Star Descriptor |
|-------------------|---|-------------------|---|
| 1 | 4**** | 8 | 4**** |
| 2 | 3*** | 9 | 4**** |
| 3 | 5***** | 10 | 4**** |
| 4 | 5***** | 11 | 3*** |
| 5 | 4**** | 12 | 4**** |
| 6 | 5***** | 13 | 4**** |
| 7 | 4**** | 14 | 3*** |

Note. The literature was assessed with the MMAT tool and results reported between 1*-5* in relation to the check list, with 1*meeting 20% of the criteria and 5* 100%.

The below table (table 3.10) presents a series of researcher notes that were made as part of the extraction of data and charting of data. The researcher made these notes to capture in some more detail the way in which lay referral had been situated, positioned and/ or conceptualised. The notes aided the researcher's thinking in terms of the cross-disciplinary nature of lay referral and how/ or if lay referral had been considered in the context of theory. The inclusion of researcher notes as part of the charting process was considered by the researcher as a positive aspect of the scoping review methodology.

Table 3.10*The Potential Theoretical Orientation and Additional Researcher Notes for the Empirical Articles*

| Number Identifier | Theoretical Orientation and Additional Research Notes for the Empirical Paper |
|-------------------|--|
| 1 | This study was situated in The Andersen Model and did not place or discuss the findings in terms of Freidson (1970). Therefore, although lay referral as a topic arose, this study did not theoretically conceptualise the process. |
| 2 | This study was situated in The Andersen Model. The term lay consultant arose as part of the findings. The study statistically described the percentage of people who disclosed their symptoms before healthcare consultation. The relationship between these individuals was also reported with a directional percentage which outlined if the lay person consulted suggested gaining healthcare professional advice. |
| 3 | This study claimed to be underpinned by the Model of Pathways to Treatment, this is the psychological model presented in the literature which builds upon and extends theoretically beyond The Andersen Model. However, a Framework analysis was employed to explore the data within and across cases, focusing on patient beliefs and experiences, disease factors, and healthcare influences and the findings were not discussed in terms of psychological theory. The paper did report that participants discussed their symptoms with friends and family although this was not conceptualised. |

| Number Identifier | Theoretical Orientation and Additional Research Notes for the Empirical Paper |
|-------------------|--|
| 4 | <p>This paper highlights and critiques The Andersen Model based upon its individualistic position and lack of focus upon relational factors. The findings of this study explain the time frame between symptom perception and help-seeking behaviour with regards to shared relational experiences and how meaning is derived through social experiences. The findings were not theoretically placed within a framework (i.e. the sociological concept of lay referral).</p> |
| 5 | <p>This study reported the importance of hard to reach and underrepresented sample populations. The background section offered an insight into how different social groups differ in regards to health status, health-related behaviours, and how people who identify as part of these groups are subjected to discrimination, social exclusion, and racism. The results of this research referred to lay consultation and collective knowledge. This paper was situated within the sociology of health and illness/ network analysis and the findings were not discussed or explained in terms of the traditional sociological theory of lay referral and consultation.</p> |
| 6 | <p>This study had a particular cultural sample population as part of the project's focus. Here, the focus was upon Hong Kong Chinese women. The rationale for this sample was that the researchers' were only able to source one previous study that explored delay in terms of Chinese women's experience of breast cancer. As part of the overall findings, lay referral system arose as one of the themes. However, the discussion section was not placed within a theoretical framework or discussed in regards to the work of Freidson (1970).</p> |

| Number Identifier | Theoretical Orientation and Additional Research Notes for the Empirical Paper |
|-------------------|--|
| 7 | This study outlined lay referral, made reference to Freidson in the introduction and referred to lay referral patterns and consultation in the write-up of the study. The findings discussed lay referral patterns in terms of life stage, age, and gender. |
| 8 | The symptom categories outlined in the quantitative survey were as follows: respiratory, gastrointestinal, musculoskeletal, emotional, or other. The rationale for categorising the selected illness symptoms in the above way, in accordance with the author was based upon their frequent occurrence. However, it is unclear as to what this means. This study defines lay referral in the context of medical sociology. |
| 9 | Lay referral, lay networks, lay consultants (lay advisors) were discussed as part of this study. Lay consultation was the main focus of the study in terms of who people spoke to and why about their illness symptoms (symptom evaluation) and self-care behaviours. Lay referral/ consultation and lay networks were not theoretically conceptualised nor discussed in regards to sociological theory. |
| 10 | Lay consultant was discussed as part of this study. The terms were not theoretically or sociologically conceptualised. |
| 11 | No researcher notes were made during the extraction and data charting. |

| Number Identifier | Theoretical Orientation and Additional Research Notes for the Empirical Paper |
|-------------------|---|
| 12 | Focus upon social network theory. |
| 13 | The findings of this study were discussed in the context of traditional medical sociological theory and lay referral. |
| 14 | This study defines lay referral in the context of traditional medical sociology. |

Table 3.11*Charted Data of the Theoretical Articles and Results Table*

| Number Identifier and Author | Discipline/ Filed | Aim | Key Points |
|---------------------------------|---|--|---|
| 15. Chrisman, N. J., (1977). | Medical anthropology and medical sociology | To relate concepts from anthropology and medical sociology to five components of health seeking- symptom definition, illness-related shifts in role behaviour, lay consultation and referral, treatment actions, and adherence. | The paper discussed previous anthropology research which focused upon illnesses among subcultural groups that obscured the heterogeneity of culture health beliefs and practices in the lay health system. The paper advocates the development of theoretical models to capture the complexity of society and suggests that research is required which stresses similarity as well as diversity within and between population groups. |

| Number Identifier and Author | Discipline/ Filed | Aim | Key Points |
|---------------------------------|--|--|---|
| 16. Ward, R. A., (1977) | Health and social behaviour | To focus on selected findings regarding older people with respect to | This paper presented previous research and focused upon selected findings regarding older people with respect to healthcare utilisation and how |
| | | three general factors in models of health care utilization. | predisposing factors/ enabling factors and illness level influence utilisation. The authors conclude that age needs to be considered in future studies. |
| 17. Litman.T, J., (1974). | Social and behavioural overview | Theoretical considerations | The article presents a social and behavioural overview of the literature. The position of the paper took into account many psychosocial factors such as family influence upon illness; economic aspects of family health; the family and the lay referral network; family health and illness behaviour; utilisation; |

| Number Identifier and Author | Discipline/ Filed | Aim | Key Points |
|---------------------------------|-------------------|---|---|
| <hr/> | | | |
| | | | source of medical care and life cycle, etc. The paper concluded with several suggestions for future research which included the continuation of research that considers how the family unit influences health and medical care, adaption to illness, adjustment, and responses to illness (with the integration of family theory). Other recommendations referred to developing different methodological approaches to this area of research. |
| 18. Zola, I, K., (1973). | Medical sociology | To describe the current literature and theoretical stance in regards to help-seeking. | This paper outlined the description of (1) a central problem in the understanding of the patient and his environment, (2) the difficulties inherent in studying this problem, (3) the insights from psychiatry and |

| Number Identifier and Author | Discipline/ Filed | Aim | Key Points |
|---------------------------------|-------------------|----------------------------|---|
| <hr/> | | | |
| | | | anthropology which made its investigation possible and (4) the first of a series of studies which ultimately was spawned out of a consideration of items 1, 2 and 3. |
| 19. Freidson, E., (1960). | Sociology | Theoretical considerations | The theoretical paper highlighted how, when systems are analysed, they sometimes are in conflict. For example, the lay referral system, which consists of a variable lay culture and a network of personal influence along which the patient travels on his way to the physician, and the professional referral system of medical culture and institutions. Differences between the systems are reported in regards to the independent practice located in the lay referral system which is primarily subject to client |

| Number Identifier and Author | Discipline/ Filed | Aim | Key Points |
|---------------------------------|-------------------|-----|------------|
|---------------------------------|-------------------|-----|------------|

| | | | controls. Whereas, dependent practice is located well within the professional referral system and is primarily subject to colleague controls. |

Table 3.12*Review Papers and Results Table*

| Number Identifier and Author(s) | Discipline/ Field | Aim | Key Points |
|---------------------------------|---|--|---|
| 20. Gottlieb, B, H., (1976). | Psychology and health service (Review type not described, presented more of a traditional literature review not a systematic review nor scoping review or other type of review). | To review the literature to summarize the existing literature. | This paper considered evidence in regards to lay influences on the utilization of healthcare services. The findings found that people seeking and receiving help is culturally/ environmentally influenced. The results identified that lay referral systems point unambiguously to that family members, friends, and acquaintances can either expedite or delay utilization of both remedial and preventive health care. |

| Number Identifier and Author(s) | Discipline/ Field | Aim | Key Points |
|---------------------------------|--|---|--|
| <hr/> | | | |
| 21. Anderson, J, G., (1973). | Health (Review type not described, presented more of a traditional literature review not a systematic review nor scoping review or other type of review). | To summarise the literature and considered recommendations for future research. | This paper explored five approaches previously used to study the utilization of health services: the sociocultural, socio-demographic, social-psychological, organizational, and social systems approach. Overall, the review suggested that social system models that develop causal structures and integrate the features of all the other approaches may provide important new insights into utilization behaviour. |

| Number Identifier and Author(s) | Discipline/ Field | Aim | Key Points |
|---------------------------------------|---|---|---|
| <hr/> | | | |
| 22. Coe, R. M & Wessen, A. F. (1965). | Psycho-social (Review type not described, presented more of a traditional literature review not a systematic review nor scoping review or other type of review). | To explore social and psychological factors in regards to the utilization of health services. | <p>The review outlined previous research in regards to medical behaviour, the doctor-patient relationship, issues around diagnosis/ treatment, and the importance of the patient's self-concept.</p> <p>Each of these areas was discussed in the context of previous research and how they influence the use of community health resources.</p> |

Table 3.13*Charted Book Chapters and Results Table*

| Number Identifier and Authors | Source of Evidence | Discipline | Summary |
|--|--------------------|-----------------------------|--|
| 23. Martin, R., & Leventhal, H. (2004) | Book chapter* | Clinical, health psychology | The chapter highlights different associations between illness symptoms and people's healthcare seeking-behaviour. The chapter was written by those who developed the Common Sense Model of Illness and the associated Common Sense Model of Illness of Self-Regulation. Evidence is presented about how symptom perception does not always lead to self-referral behaviour; that people frequently choose to manage symptoms without healthcare advice; people delay in seeking healthcare (including when symptoms may be life-threatening) and that others gain unnecessary medical advice. The chapter explores 'what makes a symptom' from somatic sensations that may lead to symptom perception, the perception of disruptive physical or psychological states and perceptions which indicate disease/ dysfunction that ignite cognitive, affective, and behavioural responses. The chapter discusses different theoretical perspectives in reference to healthcare seeking-behaviour: The Common Sense Model (CSM) of Health and Illness Behaviour; The Health Belief Model and The Theories of Reasoned Action |

| Number Identifier and Authors | Source of Evidence | Discipline | Summary |
|--|-------------------------|--------------------------|---|
| 24. Rothrock N.E., Lazarus R.S., Scheier M.F., Martin R. (2004) | Book chapter summary | Health Psychology | <p>and Planned Behaviour. Different approaches to cognitive representation of illness, maladaptive healthcare seeking behaviour, lay symptom evaluation, and how affect, fear, and contextual factors influence these processes were covered. The chapter then devoted a large discussion around the lay referral network, cultural factors as moderating variables and social identity. The chapter concludes with a real life example which exemplifies the complexity of these processes in terms of how cognitive, affective and contextual factor contribute to professional healthcare seeking behaviour.</p> <p>This chapter summary (a summary of the chapter from the encyclopaedia was sourced from the library) which formed part of a wider encyclopaedia explores the topic of lay referral networks (friends, family, and other people in the social context) that may influence people's response to illness symptoms or health threats, help label their symptoms or symptom management. The summary highlights how lay referral networks that include those who have/had experienced illness, maybe sensitized to particular illness. (The example provided was- those with a family history of heart disease may be more vigilant about recognizing symptoms of chest</p> |

| Number Identifier and Authors | Source of Evidence | Discipline | Summary |
|---|-----------------------|--|--|
| 25. Martin, R., Rothrock, N., Leventhal, H., & Leventhal, E. (2003) | Book chapter* | Health psychology, behavioural medicine, and social psychology | <p>pain or shortness of breath). The authors as part of the summary also outlined how lay consultation can encourage but can also discourage people gaining from healthcare professional advice, creating a delay in access to services.</p> <p>This chapter presents evidence in reference to self-referral/ delay and reviews the literature regarding the processes in psychological symptom perception. The focus is on presenting the author's Common Sense Model of Health and Illness Behaviour (CSM) which specifically highlights the role of illness representations, the role of affect (emotion), fear as a motivating factor, negative emotions, social context, social identity, lay referral, and how culture shapes people's illness representations. Each of these factors was considered in the theoretical context of CSM whilst considering several different social factors which also shape these processes.</p> |

| Number Identifier and Authors | Source of Evidence | Discipline | Summary |
|--|-----------------------|-----------------------------------|---|
| 26. Suls, J., Martin, R., & Leventhal, H. (1997) | Book chapter* | Health Psychology | Social comparison theory is discussed and its application during the appraisal of bodily sensations. The main focus is upon behaviour prior to people seeking healthcare advice and how people's networks enable social comparison (how values/ beliefs compare or differ), the exchange of information and how this may influence professional healthcare advice seeking. A framework is presented in which social comparison is considered in connection to how lay referral, differing symptom scenarios influence people gaining medical advice. Lay referral is then considered in the context of the illness delay stage and how lay referral may encourage and/or discourage people from seeking healthcare advice creating delay. The chapter concludes with a discussion around social comparison, lay referral, and the inappropriate use of healthcare services. Then the importance of lay referral in connection to medical consultation; outlines the implications for research and future theoretical development. |
| 27. Hamburg, K. (1979) | Book chapter | Health and Health Promotion | This chapter takes a health perspective with an overview of how social support, stress, illness may influence the use of healthcare services. Previous research which has examined the following factors was outlined: stress and social support; life stress, social support and coping strategies; affective strategies (i.e. gaining emotional support and acceptance); cognitive strategies (appraisal and re-appraisal); instrumental strategies; stress, social support and healthcare utilisation; |

| Number Identifier and Authors | Source of Evidence | Discipline | Summary |
|-------------------------------|-----------------------|------------|--|
| 28. Freidson, E. (1970) | Book chapter | Sociology | <p>the lay referral network, lay treatment network; health status and social integration; the structures of social support and their characteristics (i.e. the family unit, personal networks and help groups). The chapter ends with the consideration of how these structures of social support may also have a functional component, for instance, how mutual help groups may offer support, explores future directions of research, the role of healthcare professionals and public policy.</p> <p>This chapter discusses the lay social creation of illness from a medical sociological perspective and includes a discussion around the social meaning of pain, symptoms/ lay definitions, culture/ the use of healthcare services, the organization of entering into services, and types of lay referral systems. It is proposed that lay beliefs in different social groups (e.g., those with lay knowledge vs. professional medical knowledge; differing social class) influence behaviour. It highlights the difficulties medical professionals face with regards to reaching patients based on assumptions of differing knowledge sets. A theoretical typology is outlined in reference to lay referral systems. The 'utilization' of medical services (rate of use) is considered as the dependant variable (opposed to the characteristics of the</p> |

| Number Identifier and Authors | Source of | Discipline | Summary |
|-------------------------------|-----------|------------|---------|
| | Evidence | | |

| | | | individual who perceive the illness symptom) although no findings were presented in terms of the direct application of the typology. |

**Note.* Three of the book chapters charted as part of the review results were written by those who developed the Common Sense Model of Illness and the associated Common Sense Model of Illness of Self-Regulation and consequently present a health psychology perspective.

Characteristics of the Charted Sources

The below table (table 3.14) presents the characteristics of the charted sources this includes the theoretical/ conceptual articles, empirical, reviews and book chapters. A range of literature across several disciplines was charted such as articles from Nursing and public health (N=2), health and social behaviour (N=2), sociology (N=8), health research (N=7), general practice (N=2), social science (N=1) and psychology (N=6). The theoretical orientation of the articles is outlined in table 3.15 and the sample inclusion criteria in table 3.16.

Table 3.14*Methods and Source of Evidence Gathered as Part of the Review*

| Methods and Source of Evidence | Number (N) of Sources Found |
|--|--------------------------------|
| Empirical Studies: Qualitative (i.e., thematic analysis, framework analysis and grounded theory) | N= 5 |
| Empirical Studies: Quantitative (survey data/statistical analysis, not all methods of statistical analysis were reported) | N= 4 |
| Empirical Studies: Mixed methods studies | N= 5 |
| Theoretical and conceptual articles | N= 5 |
| Literature reviews | N= 3 |
| Book chapters | N= 6 |

Table 3.15*Theoretical Position of the Empirical Articles*

| Theoretical Position | Number (N) of Sources Found |
|----------------------|--------------------------------|
| The Andersen Model | N= 3 |
| Sociological theory | N= 2 |
| Atheoretical | N= 17 |

Table 3.16*Sample Inclusion Criteria of the Empirical Papers*

| Sample Inclusion Criteria | Number (N) of Sources Found |
|--|--------------------------------|
| Medical diagnosis (i.e. particular symptoms/ new symptoms/ stage III/stage IV breast cancer or head and neck cancer) | N= 6 |
| Specific gender (3 female, 1 male sample (with partners) | N= 4 |
| Age | N= 2 |
| Demographic factors (i.e. example, marital status) | N= 4 |

**Note.* There was a range of inclusion criteria, some with several factors

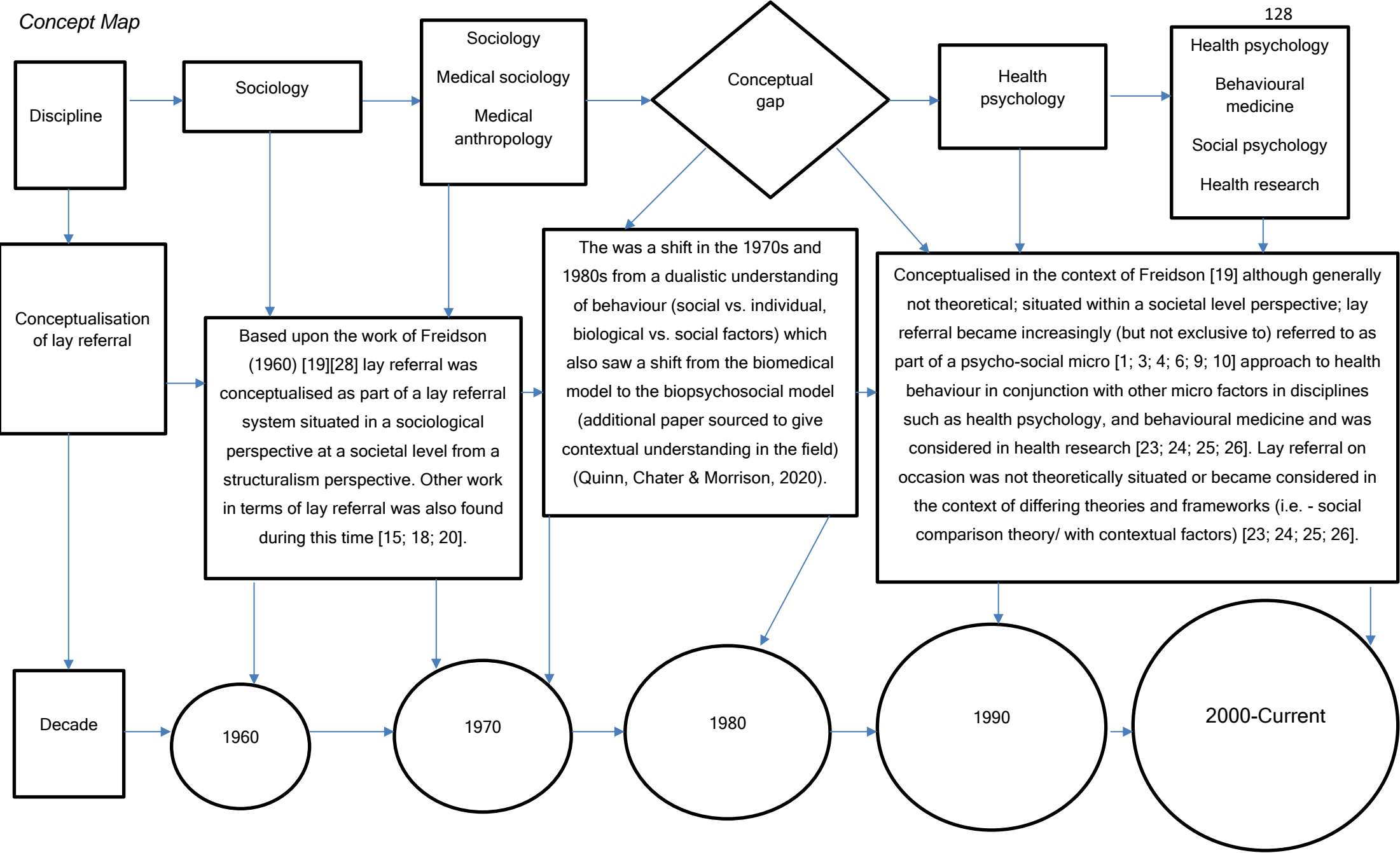
Research Question One***Stage Seven and Eight; Analysis of Evidence and Results***

The below concept map presents a visual diagram and mapping of the results generated for research question one: *'how has lay referral been conceptualised in the literature?'*. The concept map also makes numerical reference to the supporting literature which has been charted as part of the review. This numerical reference in connection to the articles can be cross-referenced to provide more information. The concept map was created to give an overview of the differing relationships between lay referral as a concept in connection to the different disciplines across differing

decades. It is acknowledged that the concept map takes a broad position in term of mapping the theoretical aspect of lay referral and is not intended to provide in depth detail but a more global perspective. Following the visual diagram below there is a narrative description to contextualise the findings of research question one.

Figure 3.2

Concept Map



The results generated through the concept map for research question one focused upon three areas of discussion which are outlined in the table below (table 3.17).

Table 3.17
Three Areas of Discussion from the Concept Map of Theory for Research Question One

| Point of Discussion | Area of Discussion |
|---------------------|--|
| 1 | Lay referral and the historical disciplinary shift |
| 2 | Lay referral as differing units of analysis |
| 3 | The conceptual gap |

1. Lay Referral: A Historical Disciplinary Shift

The concept map (figure 3.2) has enabled the researcher to visually present the results from the extracted and charted data in regards to how lay referral has been historically [19][28] conceptualised across the literature (research question one). The information presented in figure 3.2 maps how lay referral as a topic of interest to researchers and theorists developed across different disciplines from the 1960s to the 2000s and present literature. The concept map visually demonstrates a disciplinary shift in interest in lay referral, with movement occurring from the domain of traditional medical sociological, to disciplines such as health research, nursing, general practice, health psychology, social psychology, and behavioural medicine [1; 3; 4; 6; 9; 10; 23; 24; 25; 26] (see table 3.8 for numerical identifiers). This shift generally reflects a more general temporal change in the production of scientific knowledge. This is otherwise known as ‘situated knowledge’, and refers to how

under certain social conditions and periods of historical time, certain scientific knowledge is developed in a particular way and through a certain lens (APA, 2020). In the context of lay referral, situated knowledge can be demonstrated to have occurred via its journey from a sociological concept comprising lay referral systems grounded in people's social relationships and institutions (for example, social class, Freidson, 1970); to one that considered a myriad of other factors. However, during the 1960s and the 1970s, a decline in the use of structural and societal level approaches alone arose in sociology. This stemmed from a critique from the postmodern movement that argued against quantitative reductionism and claimed that these approaches placed a dualistic emphasis on social factors alone which did not account for individual factors. With the emergence of postmodernism that placed value upon discourse and lived experience (APA, 2020), lay referral became a topic of empirical interest in the health sector during the 1970s, and later in the behavioural and psychological literature. This historical shift from sociology to other disciplines has offered alternative interpretations of lay referral, and has facilitated the exploration of lay referral from the perspective of the individual within different contexts (i.e., when experiencing different symptoms). This changed focus is reflected more widely, as exemplified by the shift from the biomedical model to the biopsychosocial model. For instance, the scientist-practitioner model (which is still used today) and the use of health psychology theory to understand health related behaviours and coping (i.e., Lazarus and Folkman, as cited in Quinn, Chater & Morrison, 2020).

2. Lay Referral as Differing Units of Analysis

The analysis summarised in figure 3.2 not only illustrated the aforementioned disciplinary shift, but also depicted how the same concept (lay referral) has been studied and explored at different levels or units of analysis (which is often, but not exclusively, disciplinary orientated). For example, during the 1960s and 1970s, the analysis indicated that the majority of medical sociology and anthropology literature grounded the concept of lay referral at a societal and more structural level (which explored large social processes in regards to different groups of people as part of a wider lay referral system or network analysis). This structural approach has often been associated with a sociological functionalist perspective which views society as

a complex system in which different parts of a system work together to form different social structures that encompass the whole of society (Mooney et al., 2007) [19][28]. However, more contemporary approaches took an individual level and considered the potential psychosocial processes associated with people's behaviour [1; 3; 4; 6; 9; 10; 23; 24; 25; 26]. A micro level position refers to the exploration of individual people or small groups in their wider social context and has often been an approach used in social sciences and psychological research. This can be exemplified when considering some of the literature in the 2000s [23, 24, 25, 26] that discussed people in the context of their social worlds. This is different from micro-sociology which explores small-scale patterns of society and focuses on social interaction (Nema, 2016). This change to how lay referral has been examined as a unit of analysis is important, as it reflects the situated nature of the concept (research question one) and has also highlighted how different disciplines in differing periods of time have produced different knowledge in relation to the same topic. For example, this can be exemplified in clinical and health psychology [23; 24; 25; 26] in terms of how lay referral was considered in connection to people's individual differences (i.e. cognition and self-regulation emotion). This historical change of perspective generally (but not completely) altered that way in which lay referral was measured and understood. For instance, in terms of traditional approaches which were conceptualised/ focused upon social demographic factors [19][28]; to an understanding of how lay referral interacts and may be influenced by other psychosocial factors [23; 24; 25; 26].

3. A Conceptual Gap

As indicated in figure 3.2, a conceptual gap arose in the literature towards the end of the 1970s and into the 2000s where lay referral would appear to have not been further developed. Research within this period of time was generally situated within the discipline of health, public health, social science, or general practice research [1; 2; 3; 4; 9; 10] without reference to traditional lay referral typology [19][28]. For this reason, lay referral as a concept underwent minimal historical theoretical development and became a way of understanding how people may enter healthcare services generally without reference to the 'typology'. This conceptual gap appears to reflect how knowledge was produced during these different time

periods (i.e., situated knowledge). For example, in relation to the conceptual gap, traditional sociological conceptualisations of lay referral were informed by quantitative methods [19][28], while some of the empirical healthcare research adopted a mixed method or qualitative approach. This change in methods preferences could be attributed to postmodernism (as discussed above which focuses upon discourse and lived experience) (APA, 2020) which saw an increase in research which drew upon inductive methods (i.e., grounded theory) [3; 4; 5; 6, etc.]. This is important to acknowledge as although these inductive methods produce valuable knowledge, theory was generally generated from the data itself (bottom-up/ inductive) without the intention to deductively (top-down) consider the data concerning pre-existing ideas about lay referral. However, in accordance with the findings of this review the conceptual understanding of lay referral arose theoretically mainly in health psychology during the 2000s were, lay referral was often considered at an individual level and integrated within the existing psychological theory (social comparison theory and the common sense model of illness) [23; 24; 25; 26].

Research Question Two

Stage Seven and Eight; Analysis of Evidence and Results

A narrative summary of the thematic analysis and themes are presented below for research question two: *'how does lay referral associate with/ influence help-seeking behaviour and attendance at primary care following the recognition of bodily changes or illness symptoms?'*. Two main themes were generated through the analysis and are outlined in the below table (table 3.18).

Table 3.18*Themes Generated Through the Thematic Analysis*

| Theme | Main Theme |
|-------|--|
| 1 | Lay referral as an interconnected psychosocial process |
| 2 | Gender; samples, comparison and differences |

1. Lay Referral as an Interconnected Psychosocial Process

Findings of the reviewed empirical studies (N= 14) indicated that lay referral also involve other psychosocial factors such as avoidance of lay referral due to factors such as: stigma or social rejection; sociocultural norms related to the 'private' nature of symptoms; embarrassment; the emotional protection of others; cognitive beliefs; service barriers; gender; and age [1; 2; 3; 4; 5; 6; 7; 8; 9; 10; 11; 12; 13; 14]. Half (50%) of the charted empirical research was conducted between 2003 and 2019; with 14.28 % from 1995 to 1999; 14.28 % between 1981- 1986, and finally 28.57% from 1972 to 1973. This demonstrates that the majority of the empirical key findings (78.57%) were reported post 1970 where the empirical findings (that included lay referral) were often discussed within a psychosocial context. For example, Hall et al. (2015) discussed factors that influenced participants' symptom appraisal and help-seeking behaviour. These factors included psychosocial factors (knowledge, beliefs, illness schemas, emotion, and coping); social factors (the influence of significant others, social comparison); contextual factors (life events, socio-cultural norms, family history, previous experience of cancer); health-care factors (experience, outcomes of past consultation, access to services, relationship with the doctor, safety netting); and disease factors (severity of symptoms, onset, nature of symptoms etc.).

Hall et al. (2015) also highlighted how the participants discussed their symptoms with others (partners, family, friends, workmates, etc.) and noted that at times these discussions normalised the participants' symptoms, which then created a delay in terms of gaining healthcare advice. Consequently, Hall et al. (2015) highlighted the importance of who people speak to. The relevance of who people speak to (or not) as part of the lay referral as also found by Bonsu and Ncama (2019) whereby it was found that women disclosed their experiences with significant others, and avoided talking to those outside of their trusted social networks. A similar finding was identified by Lam et al. (2008) who found that women who experienced breast cancer symptoms typically talked to other women. Lam et al. (2008) also found that seeking professional healthcare advice was encouraged by the lay referee if they had previously experienced cancer.

The influence of psychosocial factors on the process of lay referral has also been explored for men. For instance, Forbat et al. (2013) interviewed 30 men who had been diagnosed with prostate cancer. The results indicated that the participants' relationships were important (spousal, familial, and friendships) and influenced men's help-seeking behaviour. Some men discussed talking about their symptoms with someone who had previous similar experiences; whilst others talked about delaying seeking help in order to self-manage and to emotionally protect their partners/ friends. Consequently, these results would suggest that although lay referral is socially situated, it also involves a range of other operating psychological and social factors.

2. Gender; Samples, Comparison and Differences

The theme of '*gender; samples, comparison, and differences*' was generated in relation to those studies (overall 57.1%) that included a specific gender sample [1; 2; 4; 6; 11] (i.e. an all female sample/ majority sample (N= 81 males/ N=2 female)/ all male with partners included if available) (35.7%), direct comparison of lay referral or help-seeking behaviour according to gender, or examined more indirect pathways in terms of gender influences on other psychosocial factors (21.4%) [8; 10; 14]. For example, the early study of Meininger's (1986) sought to establish whether and how males and females differ in terms of response to illness symptoms and self-treatment, lay consultation, and gaining healthcare advice. Their results identified similar behavioural responses to symptoms (i.e., no action, self-treatment, medical

care, lay consultation) however, sex differences were found following multinomial logit analysis with regards to the predictive use of lay consultation, with higher male social class linked to gaining healthcare and women who reported higher social class connected to lay consultation.

Sex differences and the influence of gender (given the period in which the literature was published the articles interchangeably use the terms sex and/ or gender) was also demonstrated by Schoenberg et al.'s (2003) mixed-methods study where the gender of middle-aged and older adults influenced whether a decision to seek healthcare was made by oneself or following consultation. For instance, women (54.3%) were less likely than men (60.4%) to recall whether they had made the decision to seek help themselves, older men were more reliant on their spouses, and older women reported having a wider lay network. Whilst actions following lay referral may differ, findings from Cornford and Cornford's (1999) study indicated that there were no significant differences between males and females in the number and frequency of lay referrals made; males consulted on average 3.4 people, and females 3.7 people. It is difficult to compare the results of these studies as they utilised different types of mixed methods and employed different sampling and inclusion criteria. For example, Cornford (1999) included people who experienced the following symptoms: respiratory, gastrointestinal, musculoskeletal, emotional, or other; whereas Queenan et al., (2017) specifically explored symptoms related to head and neck cancer with a sample which consisted mainly of men (N=81 vs N=2). This highlights the challenges when comparing research that focuses on differing symptoms, samples, at differing time points and questions what other contributing factors may have also influenced these studies i.e., the study participants had experienced differing symptoms/severity which may have also affected their coping responses. Meininger (1986) also noted this difficulty and outlined issues around generalizability in relation to the inclusion of certain sample populations. For this reason, when considering what is known in the existing literature about lay referral, it is important to take into account the socially, culturally, and historically situated nature of the research itself, the methods used, the analysis, and their findings. This is particularly relevant when considering how we understand gender and how the concept of gender may have evolved. For example, Morgenroth and Ryan (2017) highlight how thinking around gender may have evolved from biological sex alone to an identity that is developed and is reinforced through social norms. This highlights

the relevance of considering how social norms may have also influenced the findings of the above research in connection to illness behaviour and lay referral. Therefore, leading to the question of how research could incorporate a more contemporary understanding beyond traditional binary concepts of male and female categories.

Discussion and Conclusion

The findings presented offer a multitude of evidence with regard to how lay referral has been conceptualised in the literature and what factors have previously been found to influence or are associated with lay referral in connection to help-seeking behaviour. Key findings are summarised below:

- Following the original conceptualisation of lay referral and the medical sociological typology of lay referral from a societal level and structural orientation, there was a disciplinary shift across the 1970s to the 2000s. This saw lay referral emerge as an area of interest in several other disciplines outside of sociology such as in the field of health research, health psychology and behavioural medicine. Here a conceptual gap arose in the literature.
- Lay referral began to be explored at a different level rather than at the societal level, with current thinking (2000s+) considering lay referral from a micro level position within the social context.
- The literature demonstrates that lay referral involves a range of psychosocial factors.
- Gender has been found to influence lay referral following the recognition of bodily changes that may represent illness symptoms.

When considering the contribution to knowledge that this scoping review presents, the findings highlight the temporal complexity of addressing concepts such as lay referral which have been subject to decades of cross-disciplinary inquiry. The review findings represent the evolving journey of lay referral, which also encompasses growing consideration of multiple other psychosocial factors.

Limitations of the Included Empirical Studies

Limitations also rose when considering the review results in terms of the empirical literature. These limitations relate to the lack of theoretical definition or the conceptualisation of 'lay referral' in the more recent literature. This lack of definition made it difficult to directly compare the results in terms of lay referral. Other limitations related to the standardised reporting and transparency of the methods used as part of the data collection process, on occasion methods associated with the qualitative analysis and statistical analysis (e.g., the analytical strategy) (see the main table) were not reported. These differences in standards create challenges with regards to replication and a lack of standardised demographic data collection created difficulty when considering sampling bias and charting the data (i.e., on occasion demographic information was gathered). The wide variation of samples found as part of the review results in terms of different demographics also meant that it was difficult to compare the results of the empirical key findings to each other (some research has a sample with a wide age range (14-80 years) whereas other had samples had a more narrowed aged sample (65-94 years) and a range of symptoms etc. see charted data.

Conclusion

Given the current understanding of lay referral at an individual level as outlined by the health psychology literature (and other fields as discussed above), it is suggested that lay referral is explored from an idiographic perspective. This idiographic perspective may give a more in-depth insight into the psychosocial nature of lay referral following the recognition of bodily changes that may or may not be cancerous illness symptoms. Hence, a qualitative methodology that encompasses an idiographic lens and acknowledges the interactive nature between people and their social context is proposed. This is based upon the rationale that the literature (as reviewed) has employed quantitative methods, mixed methods, and/ or qualitative methods that tend to include a cross-case qualitative analysis which tends not to encompass an idiographic perspective. For example, previous research has employed methods such as thematic analysis.

Chapter Four

***“I won’t go to the doctors unless I’m dying”*: An interpretative phenomenological analysis of the perception and interpretation of bodily changes, emotional coping responses and lay referral**

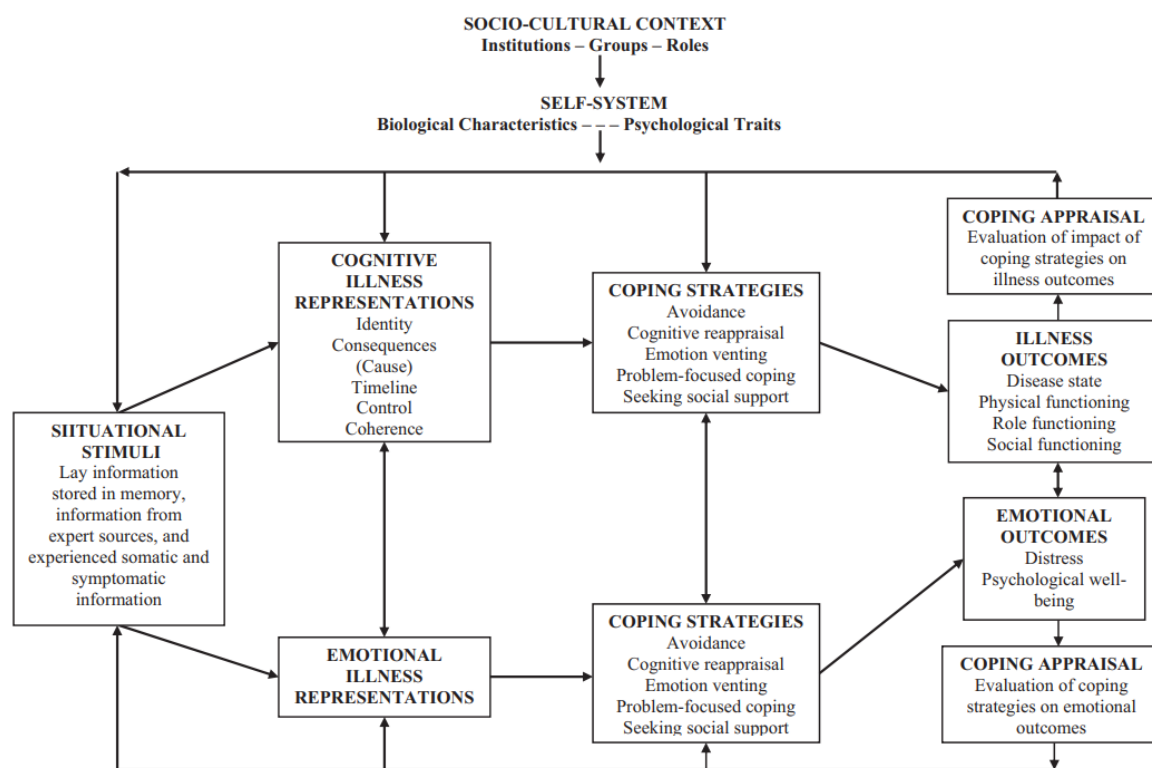
Introduction

Illness Behaviour and Health Psychology

Following the introduction of a biopsychosocial model, and psychosocial approach to research in the 1970s, help-seeking was not only examined in health research, but also in the emerging field of health psychology (Martin et al., 2003; Martin & Leventhal, 2004; Rothrock et al., 2004; Suls et al., 1997) (see Chapters one and three for more details). For example, the complexity and psychosocial nature of symptom recognition, and help-seeking behaviour was discussed by Martin and Leventhal (2004) from a clinical and health psychology perspective. They reported a range of empirical evidence which suggested that symptom perception does not necessarily lead to people seeking professional healthcare advice but instead can often result in a variety of cognitive, affective and behavioural responses (i.e. - self management, remedies, tolerating the symptoms, lay referral). Healthcare seeking behaviour was also further discussed and critically examined in the context of several different sociocognitive and self-regulatory perspectives including: The Health Belief Model; The Theories of Reasoned Action and Planned Behaviour and The Common Sense Model of Health and Illness behaviour (CSM- self-regulation of illness model) (as cited in Martin and Leventhal 2004). Based on the empirical evidence available at the time Martin and Leventhal (2004) outlined how several theoretical perspectives which aimed to provide increased explanatory value when considering people's help-seeking and decision making. For instance, The Health Belief Model (HBM) indicated that people gain professional healthcare advice based upon their beliefs/ perceptions about the severity of their bodily changes/ illness symptoms and their personal vulnerability regarding the health threat; whilst self-referral for healthcare consultation was considered to be determined by the perceived benefits and effectiveness of consultation. However, Martin and Leventhal (2004) critiqued the HBM as being unable to examine people's emotional reactions to health threats and noted that the HBM did not provide a conceptual understanding this interactive process.

Although the HBM shares some similarities with the CSM (both assume that somatic health threats ignite people's cognitive beliefs about illness symptoms), the CSM advocates that individuals make sense of their bodily changes from their

common-sense understanding of illness, and the symptoms they attach to certain illness labels (Leventhal et al., 2016). This common-sense understanding derives from the individual's knowledge which is gained from previous experience in the social context. Here the individual's knowledge and experience generate certain cognitive schema or 'illness schematics' (e.g., perceptions of what 'flu' is; 'what cancer is') stored within memory, which symptom stimuli may activate. These perceptions, referred to as 'illness representations' enter a dual-parallel processing system that incorporates both objective symptomatology ('I have a fever') and subjective cognitive ('I think this is flu') and emotional responses ('I am worried'), thus activating symptom appraisal and coping responses ('I need to self-medicate', etc.) and potential help-seeking behaviour (Leventhal et al., 1992; 2016). It is therefore the illness specific nature of CSM (which HBM/ TPB are not) and the self-regulation aspect of the CSM that moves beyond the limitations of The Health Belief Model. For instance, the self-regulation aspect of the model holds exploratory value with regards to people's responses to the perception of health threats and indicates that people affect and goal regulate through active engagement with symptoms appraisal and differing coping responses. Hence, CSM is a dynamic, multi-level processing model that incorporates feedback loops which create action in response to bodily stimuli that may represent illness symptoms (Leventhal et al., 2016; Hagger et al., 2017). The CSM model is presented below, originally based upon Leventhal, Diefenbach, Leventhal (1992) that has been developed by Hagger, Koch, Chatzisarantis and Orbell (2017) to encompasses further coping strategies and potential illness outcomes as part of the model (see figure 4.1). In consequence, the CSM transcends theories or approaches to help-seeking which either focus upon social or psychological factors alone (sociocultural, socio-demographic, organizational, and the social systems approach) (see Chapters one and two for more details) and presented an integrated psychosocial approach to symptom recognition, coping responses, illness behaviour and help-seeking (Leventhal et al., 1992; 2016).

Figure 4.1*The Common Sense Model of Self-Regulation*

Source: Hagger et al. (2017) <https://doi.apa.org/doi/10.1037/bul0000118>

Coping Responses

Coping responses relate to the individual's cognitive, emotional, and/or behavioural response to their thoughts/ emotions/ perceptions/ appraisals of illness symptoms. For instance, Suls et al. (1997) discussed lay referral (for more information about the origins of lay referral see Chapters one and two) in the context of coping responses and theoretically integrated lay referral with social comparison theory (Tajfel, 1978). Social comparison was defined as part of a process in which people compare their thoughts or opinions with other people to assess if what they think is correct, as a form of values/ beliefs and ability self-evaluation. This offered an explanatory platform that included the appraisal process, where people judge if they are ill or not by comparing if their symptoms are similar, the same, or more/ less severe than the other person or people. Symptom evaluation and appraisal were

considered across a cognitive attribution dimension as part of social comparison theory. Other aspects of lay referral were thought to include belief-value distinction in which people interpret and confirm they are experiencing an illness symptom. However, Suls et al., (1997) also discussed the complexity of lay referral in terms of behavioural 'delay' during the appraisal stage. A wide range of factors was outlined which integrated multiple different perspectives including:

- How relational factors in terms of disclosing symptoms may affect the dynamics of people's relationships or where the advice people provide regarding going to see a healthcare professional threatens the relationship itself (Zola, 1973 as cited in Suls et al., 1997)
- How people's previous experience and belief systems influence the process and the value social comparison brings in terms of the validation of the individual's own perceptions and appraisal (Leventhal et al., 1992; 2016)
- How lay referral may both encourage and discourage healthcare consultation behaviour. For example, people's differing appraisals of what constitutes a symptom or which bodily changes warrant healthcare consultation may emerge in interpersonal discussion as contradictory, or other people's previous experience of healthcare services may influence the advice they provide during lay referral.

Therefore, Suls et al. (1997) suggest that the previous experience of both the individual and those within their social networks was an important aspect of lay referral, with the process potentially also subject to beliefs of mistrust and avoidance based upon past healthcare service engagement or negative experiences. Rothrock et al. (2004) reinforced the above whilst also highlighting how the illness experiences of others (those who people speak to) may affect the process of lay referral (i.e. other people could be sensitized to particular illness symptoms or more vigilant based upon other factors such as family history or personal experience) and the advice or information people offer in regards to seeking healthcare professional advice.

The role of other people when coping with a health threat has also been examined in the context of the CSM (Hagger & Orbell, 2003; Hagger et al., 2017) (see figure 4.1). However, the role of other people in terms of coping was different

from the above and the original school of thought in relation to lay referral systems as described by Freidson (1970) from a societal and structural perspective. For instance, the role of other people was more generically considered in connection to the function of 'seeking social support' which related to how people may seek to gain emotional support and/ or instrumental support from others. Instrumental or problem-focused coping is when people seek to gain advice/ information, whereas, emotion-focused coping refers to when people seek moral support, understanding, and/ or sympathy (Carver et al., 1986). This raises the question of how or if the concept of lay referral reflects other concepts such as social support which have been integrated within CSM or if the way in which we understand lay referral in response to a health threat needs to be independently examined.

Research Question

The current study adopts a psychosocial position to enable exploration of how people perceive, interpret, and respond to bodily changes, bodily signs, and/or illness symptoms; how different emotional coping responses to illness symptoms may influence lay referral and why people seek healthcare professional advice or not. In addition, to move beyond the traditional medical sociological approach which employed quantitative methods, an inductive qualitative methodology was selected (see Chapter two for more details). The specific research question was as follows:

In what way does the perception and interpretation of bodily changes influence emotional coping responses and lay referral in the context of symptom recognition?

Method

Study Design

A cross sectional study design and an inductive qualitative Interpretative Phenomenological Analysis (IPA) methodology were selected.

Interpretative Phenomenological Analysis

Key Focus on Experience

Interpretative Phenomenological Analysis (IPA) has a particular interest and focus on people's 'experiences' (Breakwell et al., 2012). IPA in turn aims to explore

the complexity of people's experiences by focusing upon the components of the experience that matter to those people themselves that are or have experienced the topic. Eatough & Smith (2017) quote Yancher (2015) as part of their chapter (as cited in Willig & Rogers, 2017) with regards to IPA, with Yancher (2015, p.109) indicating that:

“As agents who participate meaningfully in a meaningful world, humans encounter the events of their experience as mattering; that is, participational agency is characterized by a kind of care or existential concern with affairs of living that provides a basis for action such as making judgments, taking positions, and engaging in cultural practices.” (p.7)

Consequently, due to a focus upon lived experience, IPA was considered important in relation to the topic of this study.

Phenomenology. IPA explores how people understand and make sense of their own subjective life experiences (Smith et al., 2009). The phenomenological aspect of IPA which focuses on *‘exploring experience in its own terms’* reflected the exploratory aims of the study in connection to exploring how people's own conscious perception and interpretation of bodily changes influenced emotional coping responses and the use of lay referral. This reflected the inductive, subjective, experiential nature of the study in terms of not bringing any pre-defined medical diagnostic labels to the research process to allow people to express their own subjective lived experiences from an insider position. Therefore, the focus of the study was upon people's perceptions and perceptual experiences which aligned with the phenomenological philosophical underpinnings of IPA that acknowledges how people are interconnected to their social worlds (Smith et al., 2009). Furthermore, the topic of symptom recognition, emotional coping responses, and lay referral particularly reflected Heidegger's phenomenological position (Heidegger as cited in Eatough & Smith, 2017) with regards to *‘being there’* (dasein) and *‘being-in-the-world’*. This way of situating human beings is therefore non-dualistic (in contrast to some of the previous utilization behaviour literature) and acknowledges the interconnected nature between the individual and the social context. For instance, how people connect with the world, and how the mind is connected to the body (Eatough & Smith, 2017 as cited in Willig & Rogers, 2017).

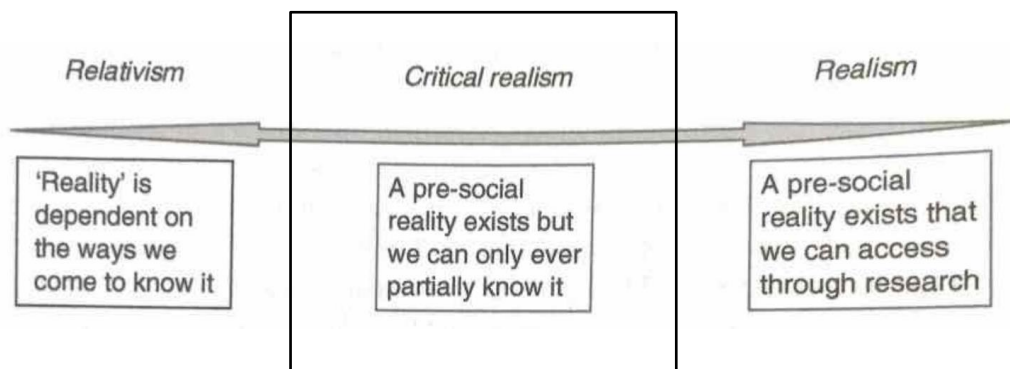
Idiography. The idiographic nature of IPA was also an important component of the approach in relation to overcoming some of the previous methodological critique in the field that made reference to group and population level research. Here, an idiographic approach is concerned with the details of people's experience from their own subjective perspective in a certain context (Smith et al., 2009). This is thought to provide depth in connection to the processes which may take place and events or relationships that may or may not be involved within the specific experience itself. For this reason, IPA was thought to offer a suitable approach that facilitated the exploration of both the individual participant's experiences whilst also offered a cross-case analysis. The idiographic nature of IPA was/is usually captured through the intentional recruitment of smaller samples so that the analysis can explore the data at both an individual and cross-case level. IPA in turn held the ability to explore both similarities and differences in the data (Eatough & Smith, 2017 as cited in Willig & Rogers, 2017).

Hermeneutics. The hermeneutic foundation of IPA offered an interpretative aspect in which the researcher engaged with double hermeneutics as part of the study. This process acknowledged the researcher as part of the process; and provided an opportunity to examine how people made sense of the topic being explored, whilst the researcher was trying to make sense of how they make sense of their experiences. This enabled the researcher to try and understand the participant's perspective with regards to the topic (Smith & Osborn, 2003). This highlighted the dual role of the researcher during the interview process, and an opportunity to acknowledge how both the researcher and the participant shared the experience of being human. In consequence, the researcher's sense-making was second order, as the researcher only had access to the phenomena under examination through the participant's expression of the experience itself (Smith et al., 2009). The importance of hermeneutics as part of the foundation of IPA can be demonstrated through the interpretative nature of the methodology. For example, Moran (2000, p.229) as cited in Smith (2019) highlights the phenomenological aspects of IPA through the below connection with the interpretative aspects of the analytical strategy:

“Phenomenology is seeking after a meaning which is perhaps hidden by the entity’s mode of appearing. In that case, the proper model for seeking meaning is the interpretations of a text and for this reason Heidegger links phenomenology with hermeneutics. How things appear or are covered up must be explicitly studied.” (p171)

Ontology and Epistemological Stance

The foundation of IPA as a methodology was thought to address some of the previous methodological critique in the field; with its ontology (the relationship between people/ the world/ interpretations and practises) (Braun & Clarke, 2013) positioned within critical realism across the ontology continuum (see figure 4.2). This position enabled the researcher to acknowledge the role of social influence as a framework of knowledge. This is different to other ontological positions such as realism, where the researcher’s assumptions suggest that there is a singular truth that can be accessed ‘*out there*’ a ‘*single reality*’ when research strategies or techniques are applied during the process (Braun & Clarke, 2013). Hence, why a contextualism epistemology was employed which is a version of constructionism (which argues that what we know is not ‘*out there*’ waiting to be discovered but is constructed through various systems/ discourses of meaning) that advocates not just a ‘*single reality*’ but that knowledge is produced in differing contexts producing differing valid ‘*truths*’ as part of the research process (Braun & Clark, 2013). The concept of ‘*truths*’ as such is rejected by constructionism and this is why IPA can be associated with contextualism with the aim of interpreting how people themselves make sense of their lived experiences in the social-cultural context (Larkin et al., 2006).

Figure 4.2*The Ontology Continuum*

Source: Braun, V., & Clarke, V. (2013). *Successful qualitative research*. SAGE Publications Ltd.

Why IPA in the Context of this Study?

The IPA methodology was selected because IPA was considered to be able to give insight into how people make sense of symptom recognition, emotional responses, and lay referral (Smith et al., 2009). IPA appeared to be a good fit in terms of the topic, with IPA developed in the field of psychology and recognises the interactive nature between different potential social, relational, cognitive, linguistic, physical, and emotional factors (Smith & Osborn, 2003). This offered a chance to move beyond the dualistic nature of historical research and theory in the field of cancer research (i.e., that focused on social factors alone). IPA was selected as opposed to other qualitative methods such as discourse analysis or grounded theory because IPA positions itself in reference to how people search for meaning in connection to their own experiences (Smith, 2019). For instance, Smith (2019) outlines how when people experience something happening to them, they reflect on it in an attempt to make sense or create meaning, and this involves both cognitive and emotional factors. Hence, IPA considers people to be self-reflexive in which the researcher can explore the experiential meaning or significance of what is happening. Moreover, people may draw upon several factors that shape their experience such as the relational aspects of their experiences, thus indicating that

people hold agency to develop reflective meaning in connection to their individual perceptions (Smith, 2019). The external socio-historical context is positively recognised and how these interconnected processes may shape each other. This is different from discursive approaches which are not concerned with the individual or experiential feelings but primarily focuses upon how identity is constituted through changing discourse within the social context and how this interacts with external social meaning systems or practices. Therefore, discursive approaches would not be able to capture some of the interrelated processes which this study aims to explore (i.e., emotion).

IPA was the selected methodology and analytical strategy which offered an opportunity to construct an unfolding narrative that expressed the participants' experiential reflections (Nizza et al., 2021). This enabled a focus upon how the participants' experiences both shared similarities and differences which helped bring meaning to the research. IPA in turn facilitated the exploration of these different factors and was considered to be a good choice in terms of the overall empirical study design (Creswell, 2013; Mayoh & Onwuegbuzies, 2015).

Method of Data Collection

Face-to-face interviews were the chosen method of data collection for the IPA study. This was based upon the potential personal nature of the interviews in connection to people's lived experience of symptom recognition, emotional coping responses, and lay referral. The topic of health and illness is considered to be 'experience type' research that people may hold a 'personal stake' in. This means that the topic could potentially hold personal meaning for the participants and in turn provided an opportunity to collect rich, in-depth experiential data (Braun & Clarke, 2013). For this reason, and intending to gain in-depth data, the study planned not to conduct focus groups or use qualitative surveys as part of the data collection. The assumption was that face-to-face interviews could provide a space in which to explore personal meaning. However, it is accepted that previous IPA research has on occasion has used focus groups as a data collection method although in accordance with Smith et al. (2009) this method can present challenges in terms of gaining people's experiential narratives instead of their 'opinions/ evaluations' as part of a wider focus group. Ritchie and Lewis (2003) also indicate that face-to-face interviews and focus groups hold differing roles in terms of data collection, with focus

groups more generally providing less of an opportunity to gather detailed individual accounts of the topic. With this in mind, face-to-face interviews were employed which present the following strengths in connection to qualitative research as outlined by Braun and Clarke (2013):

- Allows the researcher to ask unplanned questions
- Facilitates data collection as part of smaller sample sizes (for more information about sampling see below) and
- Good method to explore sensitive topics.

However, the limitations of face-to-face interviews are also recognised to include:

- That they are time consuming and resource intensive (i.e., to arrange and take place for both the researcher and the participants etc.)
- Can lack breadth (however this is not the aim of the IPA methodology) and
- That some people may find sensitive topics challenging to discuss.

Sample size

The sample size of the IPA study was carefully considered in terms of the methodology, analytical strategy, and in light of the fact that the study forms part of a PhD study. In reference to the IPA methodology, Smith et al. (2009) suggest a smaller is appropriate to enable a more in-depth idiographic analysis. The sample size was planned to be between 6-10 participants pending recruitment uptake. This ensured that enough data was gathered although not too much to prevent the researchers from becoming overwhelmed (Smith et al., 2009). The study included purposeful homogeneous sampling in which a fairly homogeneous sample was sought to increase how meaningful the study was in reference to the research question. Homogeneity in the context of IPA relates to probable shared perspective upon the topic (Larkin et al., 2019).

Semi-structured Interviews

The interview schedule adopted a semi-structured design, prepared prior to the face-to-face interviews. Open ended questions were used to allow the participants to freely respond and to talk about what mattered to them whilst also

providing a topic for discussion. The overall schedule drew upon a funnelling approach as outlined by Smith et al. (2009) in which the sequencing of questions were planned to be considered in reference to the individual questions and the overall interview schedule (i.e. more sensitive questions positioned later in the schedule to allow for rapport building and for the participant to settle into the interview); how the questions were constructed/ worded took time, and were worded in a way as to not lead the participants in a particular direction, nor to pass personal judgement or to share personal opinions. A set of probes were created and flexibly used by the researcher to explore more depth. The purpose of the interview schedule was to provide a flexible guide which did not need to be used word for word. This is different to other approaches such as structured interviews (where the questions/ response categories are pre-organised/ determined by the researcher); and unstructured interviews (where the researcher may have a list of topics/ areas/ or themes to openly discuss with the interview generally being led by the participants) (Braun & Clarke 2013). Overall, the semi-structured approach was thought to enable enough flexibility to gain in-depth experiential data in relation to the research question. The interview schedule was developed as part of an iterative process, a discussion was held with the researcher's supervisor and a pilot took place.

Sample Inclusion and Exclusion

The sample incorporated those who had experienced bodily changes and /or illness symptoms in the last three months (including currently). No incentives were provided as part of the recruitment process. Homogeneity as part of IPA sampling was considered in the context of the below inclusion criteria (for more information about purposeful sampling, homogeneity and sample size see Chapter two).

Inclusion criteria:

- Geographical homogeneity: the sample was drawn from North Wales
- Physical homogeneity: the experience of physical bodily changes / signs / illness symptoms
- Life history homogeneity: participants shared a life experience of physical bodily changes / signs / illness symptoms within the previous three months

Exclusion criteria:

- Those who lived outside of Wales
- Those who had not experienced bodily changes/ signs or illness symptoms within the previous three months

Project eligibility:

- Individuals over 18 years of age
- Were able and willing to provide informed consent (self-reported)
- Were able to communicate in English or Welsh (self-reported)

Participant Recruitment

Local Organisational Gatekeepers

Online organisational group email lists were selected through Bangor University. Individuals contacted through the organisational email 'opted in' to the project if they met the above criteria by contacting the researcher.

Local Community Notice Board Posters. Several local North Wales community organisations were invited (face-to-face, email or in writing) to display a notice board poster to advertise the study (see appendix C). These organisations included: local sports centres, Tenovus charity shops, Tenovus choir, Wrexham charity shops, Bangor University campus and Wrexham University campus. The posters presented a project summary, the researcher's contact details, and were designed in accordance with the University of Aberdeen's (2002) guidelines in terms of recruiting participants by means of a poster.

Face-to-Face Study Exhibition Stalls. Community organisations in the local town centre were contacted (in person and / or via telephone) and invited to facilitate study exhibition stalls over several weeks when convenient for the organisation. The rationale to hold the study exhibitions in the local community related to the inclusion criteria of the study in reference to geographical homogeneity. This enabled the researcher over a two-week period to introduce the study, display the written participant information sheets (see appendix D) reply slips, and consent forms. Here

people were able to take this information away with them and those who returned the reply slips via post or contacted the researcher opted into the study. This allowed for a cooling off period following the study exhibition. No risk of distress was anticipated by the team although the researcher was prepared to sign-post people to their GP for further advice (as outlined in the participant information sheet) in the event that the topic of illness and health created distress.

Procedure

Interview Schedule Development

The interview schedule (see appendix G) was broadly based upon areas identified in Chapters one and three that were considered to require further investigation from an idiographic perspective. The interview schedule was developed using the IPA funnelling approach (Smith et al., 2009) (i.e., the first interview questions were open and broad generally asking about the participants' experiences of bodily changes, then they were more focussed on how and why the participants had decided to seek healthcare professional advice or not). For more information see Chapter two.

Pilot Interviews

Five pilot interviews were conducted with people meeting the inclusion criteria from the researcher's peer network. Data collected did not contribute to the main study but were used to support the development of the researcher's interview skills, the familiarisation/ adaption of the topic guide and the IPA style interview prompts (i.e.- *how did you know you feel different; why or in what way? Can you tell me a little more?*) (See appendix G). Additional adaptations to the interview schedule included the inclusion of several opening questions to allow more of a settling in process, the interview schedule was discussed with the supervisory team and underwent an iterative process of development.

Data Collection

Ethical approval was granted by the Healthcare and Medical Sciences Academic Ethics Committee Bangor University (project number: 2017-16263-A14430). The project adheres with the British Psychological Society's Code of Human Research Ethics (2014). A Disclosure and Barring Services check was

obtained from the Disclosure and Barring Service and the researcher completed the online 2018 National Institute for Health Research 'Introduction to Good Clinical Practice' course before data collection. The participants who opted into the study were contacted and an interview was arranged taking into account the risk assessment. All interviews were conducted on Bangor University premises, and a researcher schedule that detailed the location and time of the interviews was sent to the supervisory team in accordance with the Bangor University lone worker policy.

On the day of the interviews, the participants were provided with an additional participant information sheet (see appendix D) and two written informed consent forms (see appendix E). Individual verbal and written informed consent was gained before the interviews started and copies were retained for the project records and the participants'. The participant's right to withdraw at any stage of the project was respected, should this have been the case. The interviews were voice recorded, lasted between approximately 60 – 180 minutes, and finished with a verbal de-brief and written de-brief sheet. Written forms of the Information Sheet, Consent Forms, and Debrief were provided bilingually (see appendix F). Completed consent forms and participant information was securely stored on-site at Bangor University and the interview data was securely and confidentially stored upon an encrypted one-drive (Microsoft Teams) and u-drive device in accordance with the Bangor University research data management policy.

Ethical Considerations

Welsh Language

All written information was provided in a bilingual format according to the Welsh Language Act and Bangor University Policy (2018).

Risk of Participant Distress. It was not anticipated that the interviews would cause any risk of anxiety or distress, however, in the event distress arose it was clearly outlined in the participant information that the researcher would signpost the participant to their GP for further advice. The researcher also had a service information sheet available for the participants which outlined the contacted details of local services.

Anonymity and Participant Confidentiality. In order to maintain anonymity of the data collected, pseudonyms were used on the interview transcripts as part of the analysis, write-up and these will be used within any presentations or publications.

Data Analysis

The interviews were transcribed verbatim and included a wide margin to enable analytical comment. The researcher took a flexible non-linear fluid and multi directional approach to analysis although has outlined the following steps of analysis as a broad guide (as outlined by Smith et al., 2009) (see Chapter two for more information about the IPA methodology).

Step One

Step one of the analysis (following transcription which the researcher considered part of this process) involved the researcher re-familiarising themselves with the content of the interview(s). This was achieved through an active engagement with the data from reading and re-reading the transcript(s), and listening to the audio recording of the interview(s) several times.

Step Two. Step two at times merged with step one. Here, as the researcher became familiar with the data with a focus upon one transcript at a time, the initial underlining of data on a hard copy of the transcript, free associating and written notes related to what appeared to be important to the participant in the data began. The initial comments were mainly descriptive, had a phenomenological focus (i.e. highlighted key points linked to: relationships, processes, place, events, values) and the participants' thoughts and experiences (assumptions, emotional responses). The researcher wrote notes relating to linguistic aspects of the data (i.e. pauses, laughter, metaphors and repetition). This facilitated an interpretative position in which the researcher's notes enabled a move towards a conceptual analysis (provisional meaning connected to the researcher's professional knowledge) of each participant's interview transcript (see appendix H for an extract). Here, the analysis stayed close to the participant's words although it moved away from the explicit claims of participants to an overarching notation of the topics being discussed which opened a variation of provisional meanings. The process of reflexivity supported the conceptual analysis, and allowed the researcher to reflect upon her interpretations.

Step Three. Step three involved the researcher returning to the transcripts and noting/ generating theme titles to capture meaning. The themes were generated through a process of exploring the data (although there was more of a shift towards the researcher's notes rather than the focus solely upon the data at this point) and how/ were connections/ associations, similarities/ differences or contradictions arose across the data/ researcher's notes. The focus also at times would move between certain aspect of the transcripts to overall and broader considerations. Themes were then translated into phrases that captured the psychological essence of the participants' lived experience with regards to the topic. This enabled a theoretical connection grounded in the richness of participants' discourse and related to the interpretative nature of IPA which moves beyond descriptive level analysis. The themes were listed in the order that they came up in the transcript which aimed to express an understanding of the topic through both the participants' narratives and the researcher's analysis.

Step Four. The themes listed as part of step three were then iteratively developed and re-developed by the researcher (with some discarded) when considering how the themes fit and connect together. Here a process of mapping took place in which the themes were considered in light of the research questions. This enabled the researcher to explore differing meanings and to develop a structure that highlighted what was important to the participants. The process itself was labour intensive, with the researcher printing out the list of themes produced as part of step three on separate process of paper and using the floor as a space in which to map, group similar or dissimilar themes, to develop and move around the themes when creating a meaningful structure. Several strategies were drawn upon when exploring the connections between the themes as part of stage three which included the below (based on Smith et al., 2009):

- Abstraction

The identification of patterns between the themes, where a new name is developed for the cluster and potential super-ordinate themes.

- Contextualization

Examining connections in reference to the themes in order to explore contextual factors or narrative components within the analysis (i.e., temporal aspects).

- Function

Themes were considered in light of their function and how they add depth to the experiential narrative being expressed through the analysis and theme generation

- Polarization

The exploration of oppositional relationships between the themes and exploring differences.

Following the above process, a table of overall themes was produced.

Step Five. The above process was repeated when moving on to the next transcript.

Step Six. Step six involved the researcher exploring patterns across the analysed data from the seven interviews. Here, connections between each transcript were considered, in terms of which themes supported other themes and how they support each other to give depth to the themes. Themes were re-developed/ re-labelled and explored at a theoretical level during the interpretive process. Here the researcher's previous psychological knowledge was drawn upon to support and engage with the double hermeneutic nature of IPA . The researcher's interpretative sense-making was second order through the participant's expression of the topic. By engaging with this process and integrating the researcher's interpretative frame of reference, the analytical strategy moved beyond descriptive level analysis. Several super-ordinate themes were developed that represented an overarching theme and often encompassed several sub-themes that reflected certain important aspects of the super-ordinate theme itself. The inclusion of sub-themes provided narrative and experiential depth to the super-ordinate theme which gave further insight to the participants' lived experience. An overall main table of themes representing all participants was developed. For information with regards to quality and the mini audit of analysis see Chapter two.

Reflexivity

For more information about the role of reflexivity in relation to this study see Chapter two in reference to quality criteria.

Participants

Seven voluntary participants were consented to take part in this study. The sample incorporated those who have previously experienced bodily changes and /or illness symptoms in the previous three months (see above for inclusion criteria). The below table (table 4.1) presents the participants' information.

Table 4.1

Participant Information Table

| Pseudonym Name | Recruitment Method | Age in Years | Bodily Changes |
|-------------------|----------------------------------|-----------------|--|
| Violet | Exhibition stalls | 71 | Fatigue, physical stiffness and coughing |
| Marie | Exhibition stalls | 61 | Physical pain, weight gain, vomiting, fatigue, aching |
| Laura | Local organisational gatekeepers | 32 | Abdominal pain |
| Faye | Local organisational gatekeepers | 48 | Physical pain, aching, weight gain, painful hip, uncomfortable breasts |
| Megan | Local organisational gatekeepers | 38 | Headaches |
| Jane | Exhibition stalls | 60 | Changes in blood circulation, physical stiffness |

| | | | |
|-----|-------------------|----------------|---|
| Kay | Exhibition stalls | Late adulthood | Fatigue, bleeding gums, physical tingling / cramp, bruising and brain fog |
|-----|-------------------|----------------|---|

Results Section

Themes

Five main super-ordinate themes were identified from the analysis and are labelled as follows: *‘recognition; an entangled cognitive, emotional and relational process’*; *‘the effect of affect’*; *‘relationally shaped illness behaviour’*; *‘lay referral; relational and emotional affect’* and, *‘divergent help-seeking behaviour’*. Each main theme contained sub-themes as described below.

Table 4.2

Table of Main Themes

| Main Super-ordinate Themes | Sub Themes |
|--|--|
| Main theme one: Recognition; an entangled cognitive, emotional and relational process | <ul style="list-style-type: none"> • Health and illness as an experiential ambiguous continuum • Relational recognition |
| Main theme two: The effect of affect | <ul style="list-style-type: none"> • Cognitively and emotionally mediated interpretation • Ambiguity and affect-regulation |

| | |
|---|--|
| Main theme three: | <ul style="list-style-type: none"> • Unattuned and previous adverse familial relationships |
| Relationally shaped illness behaviour | <ul style="list-style-type: none"> • Intergenerational reflections regarding lay referral and help-seeking • Unattuned and previous adverse healthcare experiences |
| Main theme four: | <ul style="list-style-type: none"> • Making sense of maladaptive lay referral |
| Lay referral; relational and emotional affect | <ul style="list-style-type: none"> • Expression and repression shaped lay referral • Lay referral and the acquisition of online information |
| Main theme five: | <ul style="list-style-type: none"> • Active help-seeking and consultation |
| Divergent help-seeking behaviour | <ul style="list-style-type: none"> • Avoidance and/or non-consulting behaviour |

These super-ordinate and sub-themes illuminated the way in which the participants made sense of how they perceived and interpreted their bodily changes, and how these processes influenced their emotional coping and use of lay referral in the context of symptom recognition.

Theme One: *Recognition; An Entangled Cognitive, Emotional and Relational Process*

This theme captures the participants' perceptual recognition of ambiguous and inconsistent bodily changes. For the participants, health and illness appeared across an experiential continuum of ambiguous, fleeting bodily changes, entangled with a change of emotional states. There was no absolute recognition that their

bodily experiences indicated illness symptoms as categorised by the medical model. For some, the recognition of bodily changes was ignited and reinforced in the relational context; whilst others drew upon the visual and physical features of their experience. Negative emotion arose throughout the recognition process and highlighted the difficulty that the participants encountered when their bodily changes were not salient enough to cognitively represent or be appraised as typically known illness symptoms. This was apparent as the participants reflected upon their experiences prior to the interpretation of their bodily changes, emotional responses, and lay referral.

Health and Illness; An Experiential Ambiguous Continuum

This sub-theme denotes how the participants perceptually noticed, recognised, and experienced their ambiguous bodily changes although their bodily changes held no obvious meaning, label, or medically categorised illness symptoms to reflect their experience. The perception and recognition of bodily changes arose across an experiential temporal continuum of both fluctuating physical and emotional changes. For example, Megan's recognition of her bodily changes followed the experience of inconsistent and fleeting bodily sensory experiences and she described how she would '*let them be*' as '*they would normally pass*'. The notion of an experiential continuum between health and illness also became evident where, Megan made reference to being '*well enough*' to carry on - not ill enough to stop whatever she was doing:

"... They would just normally pass... I just let them be-... they would get better or enough- well enough- that I could then (.) do whatever I was doing..... I was never (.) scared, "Oh my god..."

(Megan)

Marie, like Megan, reflected on her experience of bodily changes and painful bodily sensory experiences. Here, the focus was on how these sensory experiences altered and/or changed the way in which she physically, emotionally, and temporally experienced herself across '*moments*' or different '*days*'. Marie expressed surprise and upset in regards to her bodily changes and articulated a sense of distress,

inferring that her *'illness symptoms'* would *'plays games'* with her. The way in which Marie described her own experiences in connection to her *'illness symptoms'* that would *'play games'* appeared to objectify or disembody her bodily changes or experiences. Marie appeared to describe a level of metaphoric psychological distance between herself and her illness symptoms in light of her experience of *'shock'*:

"...I get the symptoms... like you're sunburnt, the pain... like burning pain. And even joint pain.... like someone's pricking you with a needle... The worst part was, I was shocked-..... Cause sometimes it plays games with you... moments when they're mild... moments or days when they're quite strong"

(Marie)

For Violet, her physical bodily changes ignited a perceptual awareness and recognition of her bodily changes. Violet removed her shoe to show the researcher her foot during the interview and this non-verbal communication appeared to confirm the existence of her self-observed bodily changes. Through the interview process itself, Violet's foot became an object of observation and discussion. A sense of bodily objectification arose, and the researcher almost become part of the process. This objectification of bodily changes reflected the way in which Marie articulated her experience's:

"But I have noticed a change in me bones... (.) they stick out more... and I think my wrists have got thinner [laughs] as well, it's one of the only things that has got thinner... On my foot, you can't see it but I will just show you (.)... That sticks out, that bone, there..."

(Violet)

The experience of bodily changes and how people make sense of their experiences appeared to be a challenging process which encompassed multiple different factors.

Relational Recognition

'Relational recognition' refers to how the recognition of bodily changes was heightened when considered in the context of previous temporal workplace, social experiences, and self-related expectations. For instance, Marie described herself as a *'perfectionist'* in work and reflected on how she felt different when she was no longer

able to perform to her own high standards as a *'perfectionist'*. Marie powerfully metaphorically described her bodily changes and insinuated that a part of herself (as a *'perfectionist'*) had been *'washed away'* through a physical and emotional *'tsunami'*. The emotional distress ignited through her sense of loss in terms of relating to her own workplace perfectionism led to a heightened perceptual awareness of her ambiguous bodily changes. Through Marie's reflections about a discussion with her manager, we are able to observe the temporal complexity of her experiences. Her expectations of herself in the wider relational context were apparent which had also been disrupted through her ambiguous bodily changes and were reinforced through her communication with her manager:

"... I'm quite a perfectionist; I really want to do things the proper way... And I... went to work, and I could feel something not right with me, I couldn't focus... I was trying to do my job. I started feeling achy... (.) like a tsunami came all over me. I felt like, "Hang on, this doesn't feel right." ... I started getting quite... my confidence had been away from me and thinking the worst of me... as if you've got no more logic left in you... But it worried me because I was working... I didn't wanna make mistakes... I felt embarrassed... I could hardly walk... So, I had to go see my manager... she knew me because she interviewed me... and... I said, "Look, I don't think I'm right. " She said, "Actually... I can see in your eyes." (.) And I thought, "Pardon?.. What?" And she said... "I know you can do your job otherwise I wouldn't have employed you."... "You need to go home."

(Marie)

Similarly, Kay noticed a difference when her speech, thoughts, and activity became disrupted during her interpersonal interactions. This temporal difference in the way Kay experienced herself elicited negative emotion, a sense of loss, and sadness, recognised not only by Kay but also by her friend:

"...words that would normally just flow off my tongue, I'm having to stop and think. ... "What does that mean?" because it's affected my thought processes and they're not as quick as they used to be..... I just felt... this isn't me. I don't feel like me... my friend, said, "You've lost your spark, Kay, what's happened?" ..."

(Kay)

As part of the participants' recognition, they did not compare themselves to others in order to make sense of their experiences but drew upon temporal information about themselves in connection to others.

Theme Two: The Effect of affect

This theme '*the effect of affect*' denotes how the interpretation(s) of bodily changes were cognitively informed but more generally emotionally mediated. Emotionally mediated in terms of how the participants thought about their bodily changes and how they provided multiple interpretations when there was no obvious label to attach to them. This ambiguity created relational uncertainty and negative affect. This illuminating the emotional and relational aspects of the interpretive process. Furthermore, the interpretation of ambiguous bodily changes is seen to vary in order to emotionally regulate (i.e., manage her emotions) given the uncertainty.

Cognitively and Emotionally Mediated Interpretation

The sub-theme of '*cognitively and emotionally mediated interpretation*' highlights how the interpretation of bodily changes was informed by pre-existing beliefs and was emotionally mediated (i.e., interpretation(s) on occasion were possibly avoided or mediated when the meaning of certain labels associated with specific health conditions increased negative affect). This can be exemplified through Megan's account of how she enters into a psychological 'tug of war' between her interpretations of what her bodily changes may mean. At one end of the rope is the '*menopause*' and at the other is '*anxiety and stress*'. Each potentially emotionally mediated as Megan explained that her thinking was '*subconscious*'. This suggests that she was not totally aware of why she thought that she may be experiencing the '*menopause*' which '*struck a chord*' of emotion. Megan questioned her experiences, with not '*knowing*'. Her '*worry*' is not only about now but also about the future:

"... My subconscious just kind of said, "Oh, it's ["definitely the menopause"?]. ... And I know that anxiety and stress can lead to many things... I had been very stressed..... But the word "menopause", that one... struck a chord... I still don't know whether it was or it wasn't... I'll just wait and see..... I'm a pretty obsessive person... That's the worst. I'm not with the present... I'm already way ahead.... that

brings the worry when I'm thinking about menopause and I think... I'm 50 and I'm not."

(Megan)

As for Megan, Violet also made sense of her bodily changes based upon her previous knowledge and illness experiences. However, she also expressed confusion and provided an incoherent interpretation of her 'liver' condition. In order to create meaning from her confusion and uncertainty, Violet reflected on previous hospital appointments. She continued to question why she had not asked for more information about her 'liver' condition although she proceeded to dismiss her own thoughts in an attempt to potentially avoid the interpretation of what could be a long-term condition. Violet's dismissiveness and potential interpretative avoidance in regards to her 'liver' condition which could have serious health consequences (i.e. - result in a low 'immune system') appeared to emotionally mediate her unknowing and protect her from the reality of her health condition:

"... I think that's connected to the (.)... not the liver...the bones and that, isn't it sort of thing (.) it's all connected. And then there again, the liver, then they said (.) I can catch, the immune system, I can catch... all sorts... of things..... I wish I was more help really (.) because I can't think... last time I went to hospital I should of asked more questions, but seeing the bloods alright, I must be alright..."

(Violet)

It would appear that ambiguous bodily stimuli can create or elicit a spectrum of emotional responses when people temporally make sense of their experiences.

Ambiguity and Affect-Regulation

This sub-theme moved beyond the participants' emotionally mediated interpretation of ambiguous bodily changes and uncovered how the participants appeared to experience increased interpersonal/ relational uncertainty and affect-regulation. The below excerpts exemplify the significant influence of affect-regulation beyond the physicality of their experience. Kay discussed her anxiety concerning death and potential relational separation following the fluctuating progression of her bodily changes. Kay's account clearly expressed the difficulties associated with

relational separation elicited through the experience of bodily changes. As Kay reflected the emotional aspects of her experience in connection to her family were apparent as she *'wanted to leave specific pieces of jewellery.... granddaughters'*. In response to the uncertainty of her health, she had *'wills made'*, as her bodily changes increased, she experienced a sense of fear *'I can't do this...'*. Kay's changing feelings of disappointment, frustration, anxiety, and sadness was apparent:

"... I was beginning to think... obviously we have wills made...been to the solicitors cause I'd wanted to leave specific pieces of jewellery (.) to our granddaughters...I felt well when we started... and then as I started to feel worse, I thought, "I can't do this because very, soon, they're going to be reading this out because I'll not be here..... I sometimes think, "I just want to be able to do what I used to do. And it makes me feel- I wouldn't say depressed in the clinical sense, but it makes me feel a bit fed up."

(Kay)

Jane's account also illuminated the interconnectedness of emotion and physical health. Jane revealed the on-going severity of temporal/ seasonal episodes of depression in which her body *'shuts down'* and when she *'can't get out'*. It would appear in order to emotionally regulate; Jane draws upon her own resources and *'shut(s) down'*. Jane reflected upon her separation from the world during these times which created an experience of depression:

"Yeah, I-I do get quite depressed um (.) ... especially in the winter, because I can't get out, because when it's cold... my body sort of shuts down. Um (.) it just cannot cope ... that does get me depressed..."

(Jane)

In contrast, Marie discussed how the *'invisible'*, ambiguous and undiagnosed nature of her bodily changes created increased her experience of anxiety. Marie expressed fear, her need to manage her emotions, and was aware that other people did not believe her. This became even more apparent in the interview itself as Marie declared that she was speaking honesty. This highlighted Marie's experience, a lack of relational responsiveness from others, a sense of experiential separation and disconnect:

“... It’s so invisible, what I’ve got, it makes you think I’m putting it on... I’m just pulling a fast one... And that, again, it’s actually given me a knock-on effect on my stress level. So it’s a vicious circle. And I am honest, you know?”

(Marie)

It appeared that the ambiguous nature of bodily changes led to feelings of interpersonal/ relational uncertainty, separation, anxiety, depression, fear and sadness.

Theme Three: *Relationally Shaped Illness Behaviour*

The theme, *‘relationally shaped illness behaviour’* illuminated how the participants’ previous temporal social experiences and relational background provided a reflective insight into how they have individually learnt to communicate about their health. This comprised of three sub-themes: *‘unattuned and adverse familial relationships’*; *‘intergenerational reflections; lay referral and help-seeking’* and *‘unattuned and previous adverse healthcare experiences’*. In summary, this theme captures how the participants spontaneously temporally reflected on their family relationships, and illuminates how intergenerational and interpersonal communication similarities arose. The relevance of intergenerational and unattuned (i.e., inconsistent and/or unpredictable relational responses towards the participants) experiences became significant in regards to family norms, how the participants had learnt to make sense of their bodily changes, who they had previously discussed these experiences with (or not) (lay referral), and their help-seeking behaviour. Previous negative experiences of using healthcare services and of healthcare professionals also became apparent when most participants reflected upon their current experiences of bodily changes and professional healthcare seeking. The previous negative experience of health care services and healthcare professionals who lacked individual responsiveness to most of the participants’ needs (6 out of the 7) often resulted in maladaptive help-seeking. In addition, for several of the participants some similarities arose with regard to their previous family experiences (the first two sub-themes). These difficulties were not confined to their previous family relationships but were frequently discussed and reflected how they spoke about their more recent interpersonal communication with healthcare professionals (the last two sub-themes). The importance of the family context, as an interpersonal

relational foundation which often influenced (throughout the later main themes) the participants' more recent recognition, interpretation, emotions, lay referral, and help-seeking behaviour in response to their bodily changes was highlighted. This theme captures contextual, relational, and temporal insight to the participants' background/family history. All of these points offer a valuable narrative foundation to the participants' lives.

Unattuned and Adverse Familial Relationships

The sub-theme '*unattuned and adverse familial relationships*' reflects the participants' difficult, challenging, and what appeared to be sometimes unresponsive, past/ prior family relationships. For some, these relational challenges arose throughout childhood, across the life span, and for others more recently. Their experiences although similar in terms of family context also differed and gave insight to the participants' life span relationships. For instance, Jane described how she believed other people perceived her, reflected upon her mother's eating disorder, unattuned, dismissive, inconsistent parenting (between her siblings), and how she had learnt to be '*self-contained*' in childhood. For Jane, these relational difficulties continued into her adult relationships and can be witnessed when she asserted '*I don't care I'm Jane-no-friends*':

"...I'm...happy people thinking, "oh my god... boring Jane." ... I don't care I'm Jane-no-friends... I'm quite self-contained, having had to learn that from a young age..... My mother was very much an eccentric... probably because of her dyslexia... she struggled mentally... suffered with anorexia when she was younger... we were always dismissed... three of my siblings went off to boarding school ... three went to comprehensive... it... divided the family... caused considerable friction over the years..."

(Jane)

Jane also discussed her children and step-children in the interview, with Jane expressing both challenges and learning for her own daughters:

“... My stepson is living with us (.) and he’s a drug addict but will not face the fact and neither will my husband, you know...It-it grieves me but er in one way it’s a learning curve for my daughters...”

(Jane)

As with Jane, Violet also temporally discussed her family history, although she focused on her deceased brother. Violet reflected on his difficulties when she was younger, which for a period had not been noticed by professional services. As Violet spoke about a distressing situation for both her and her brother, she acknowledged that she had experienced a lack of understanding following the event. Violet attributed this to a lack of discussion, as the event ‘...*wasn’t talked about*’. Violet suggested that her brother may have been ‘*embarrassed*’, hence why they did not talk about it. In retrospect, Violet expressed a lack of communication between them and that her brother had been let down by professional services, although he had previously made ‘*a cry for help*’:

“... when we were young... he was naughty... in them days no one picked up on his whatever..... the police (.) must of come, but nothing materialised... nothing as far as I know because it wasn’t talked about... he did have mental problems..... use to take overdose because it’s a cry for help... But he was lovely... me brother wouldn’t tell me nothing because he was embarrassed probably wasn’t he... the police picked him up... it was in the paper and then his social worker... he said ‘it won’t be it’... I was there when he passed away, I was... he died...”

(Violet)

Similarly, Marie discussed family difficulties although they were different to Violet. Marie’s narrative focused upon several prolonged and difficult family experiences during her adulthood. Several members of Marie’s family had experienced: near death experiences, life threatening disease, and psychological distress. In response, to these potentially life changing and life-threatening experiences, Marie made sense of her own bodily changes in light of these adverse family events. The way in which she reflected upon these experiences gave contextual insight to Marie’s family history, her relationships, potential relational separation which all lay the foundation of how she makes sense of her bodily changes. Marie strongly felt that her physical health,

psychological wellbeing, and career had all been all been affected through the stress she has experienced:

“... these symptoms, if I’m gonna say all this is stress-related... but in the past, there were other things... my husband... almost died... contracted MRSA and no one told me... just sent him home to die... I had to give up my work. It was a terrible time... My son was in intensive care... his organs were shutting down... I had both of them... My sister had a breakdown... because she worries... my dad was ill... my aunt died of cancer but that same week my son found out he’s got cancer. It’s so much... You look at me now...”

(Marie)

Marie not only discussed her familial experiences which created stress but her work place experiences:

“...I-I-I really was very um (.) looking forward to this job, purely because my last job ended up quite in a bad way. I was bullied. And this probably had a knock-on-effect as well- on top of my other trauma. And maybe my body said, “Hang on, no more.”

Through the participants’ temporal reflections, the reader is able to gain a sense of how they drew upon their relational experiences when thinking about their current experiences. In order to make sense of the present, the past became relevant.

Intergenerational Reflections; Lay Referral and Help-Seeking

This sub-theme uncovered the similarities between how the participants described the way in which their family talked (or did not) about illness in their childhoods, and how they recently talked (or did not) about illness in their present adult relationships. Lay referral was also discussed in the context of both their past and current experiences. For instance, Jane placed positive emphasis upon how her family had previously endured hardship and pain whilst not verbally expressing any form of emotion to each other. Jane emphasised how this ‘stoic’ characteristic was shared by both of her parents in childhood. Jane had no recall of health-related discussions, lay referral, or attending any healthcare services in her early years:

"...I've been lucky...my family... are (.) very stoic...we were b-brought up like that...my mother, if you showed you were ill, oh, goodness me there's somebody down the road much iller than you! How dare you say that! So, I think it is an attitude, you know. Um... My father... he fought as a marine in the er army (.)...he got malaria and came back and then of course they patched him up and sent him out... so he knew all about being stoic... you get on with it, you know? ... I (.) don't ever remember us going to the doctor when we were little... but he was on steroids for 40 years"

(Jane)

Jane then discussed her perceptions of herself as the *'runt of the litter'* and how she retrospectively felt dismissed by her parents during episodes of illness. Jane directly compared this to her adulthood experiences of her husband's family and suggested that her health was, *'an elephant in the room'*. A part of her life when with her husband's family that is hidden and not discussed. Jane discussed avoiding health related discussions in her present relationships arguably learnt through childhood, although the health difficulties Jane face following her service in the army after the *'gas chamber'* incident are apparent:

"Um I'm one of six children but I'm definitely the runt of the litter... I was a soldier in the army... they use to put is in um-.... You would have to go into a gas chamber... and put all these outfits on... which were supposed to... protect... but one day, we did have a gas, but I'm not sure what gas it was... we had to take our gas masks off, say our number... I remember after that, I did not feel well. And I can say from then on, it felt like I never felt well... I had to leave the army which was devastating..."

"My mother and father were the same... "...shut up and get on with it..." You know, you've got to find a way yourself... But I see it... with my husband's family... There's always an elephant in the room... I try to...keep that... what affects me in my relationships- away from- ...that's the only way you cope with it... I keep my health problems to myself 'cause I know that I can battle it out myself..."

(Jane)

The intergenerational nature of another participant, Megan's, health communication is exemplified below when she directly compared the relational nature of her current

adult relationship with her parent's relationship as observed in childhood. This temporal reflective comparison illuminated how family norms may shape adult relationships in terms of help-seeking behaviour and lay referral:

"...he's not the most sympathetic... struggles to empathise... quite dismissive..... we don't have long conversations about our health ... he wouldn't really be the first person I would tell..... My mum, completely the same... She didn't moan to my dad when we were growing up... She still doesn't moan to my dad... definitely you become you mum... and I [laughs] am becoming my mum a lot ..."

(Megan)

Laura reiterated the significant impact her parents' behaviour has had on her own help-seeking behaviour. For Laura, her '*instilled*' almost embodied family beliefs have continued to influence her decision making and have possibly created a period of delay as you do not go to the doctors '*unless you're dying*':

"... my dad wouldn't go to the doctors; my mum would only go to the doctors if it was serious. So, it sort of instilled into me, "Don't go unless you're dying," kind of mentality."

(Laura)

The above illuminates the intergenerational and embodied nature of lay referral and the participants' help-seeking.

Unattuned and Previous Adverse Healthcare Experiences

The sub-theme of '*unattuned and previous adverse healthcare experiences*' gave further temporal and contextual insight. For some, they expressed the experience of difficult, unattuned (inconsistent and/ or unpredictable relational interactions) or challenging relationships that moved beyond their families. These experiences related to their own previous experience of healthcare professionals and wider systems of care. Most of the participants (6 out of 7) described how their previous interactions with healthcare professionals lacked responsiveness to their needs, thoughts, perceptions, and emotions. For example, when Jane spoke about a medical consultation, she specifically expressed a negative view of him, questioning his knowledge and insinuating that his unpredictable, unattuned response towards

her as an individual was due to his prejudice towards women. However, Jane's narrative again also alluded to a negative self-perception that led her daughter to accompany her to the next healthcare consultation. Help-seeking became a shared relational process, as Jane's daughter reinforced her negative views of the consultant:

"I did see er a-a gastro (.) consultant ... He wasn't the man for me [laughs]... I did ask him, had he met anybody with, you know, had been on long-term steroids... like myself.... I don't think his personality could take being questioned... which is a shame... Maybe it was my... approach... He had a light air of misogynist... I took my daughter who is... a bit more intelligent than me... which is not difficult of course... she could see it from a more professional sort of a-attitude... she thought (.) no, he wasn't helpful."

(Jane)

Similar to Jane's experiences, Marie's previous experiences of help-seeking appeared unattuned, and lacked responsiveness to her emotional needs. In consequence, help-seeking became maladaptive when she left a healthcare consultation with no additional knowledge than when she had entered. This lack of medical clarity and inconsistency in terms of her expectations led to frustration and confusion, which resulted in Marie, articulating a repeated need for the 'doctor' to help her understand her bodily changes from a medical perspective. However, Marie differed from Jane in that she directly expressed her emotional frustration with the healthcare professional and her bewilderedness when her personal expectations and needs went unmet by the doctor:

"... I even told the doctor, not off, but told them in... diplomatic way. They said "Oh, it's the menopause." "No," I said, "Please don't give me that anymore." ... "I've been through it. Don't label as menopause when you don't know." I wanted the doctor to tell me... And he did say it's very hard to diagnose things like that... he still found it hard, the doctor to actually tell me... So last time I saw him, I said, I've got to go and see the occupational health. What shall I tell him I've got? Because you don't know, I don't know, you tell me."

(Marie)

In contrast, Laura's previous negative experiences of healthcare professionals influenced how she made sense of her present non-consulting behaviour. Her non-consulting behaviour was based on a firm belief that she was unable to trust, rely or depend on the medical profession. These beliefs were based on and shaped by Laura's earlier childhood lived experiences (e.g., hospitals= death) and previous experiences where her needs went unmet. Laura expressed 'feeling unheard' by healthcare professionals, which had a significant impact on upon Laura's current help-seeking behaviour; Laura declared that she would not "*attend the doctors*" unless she was dying. The below conveys the relational challenges that she has experienced in the patient-doctor relationship, and highlights the potential serious consequences when wider systems of care do not meet people's individual needs:

"... I don't go to the doctors... I don't trust them... a few years ago I injured my foot... the doctor didn't care... all he cared about was checking my blood pressure... so I hobbled out of there with nothing... I don't trust the doctor's... Doesn't matter how much pain I'm in, I won't go to the doctors unless I'm dying... I was afraid of the hospital... when I was younger, people went into hospital and they died, so I associated it with death... So I thought, giving birth in hospital, I'll get used to it, I'll lose my fear, but it actually made me worse because the professionals didn't listen to me and I had a mental breakdown the day after I gave birth. So (.) don't trust the professionals at all."

(Laura)

Through the participants' narratives, the significance of their relationships is clear. The importance of not only their close relationships arose but also their relationships with healthcare professionals and the impact of this can have upon help-seeking behaviour.

Theme Four: Lay Referral; Relational and Emotional Affect

The main theme of '*lay referral; relational and emotional affect*' uncovered how the participants made sense of previous health conversations and lay referral in their adulthood. For some, lay referral had resulted in unhelpful relational interactions

with others, an increase of negative emotion, and relational avoidance. The long-lasting impact of these experiences can be observed below.

Making Sense of Maladaptive Lay Referral

'Making sense of maladaptive lay referral' outlines the participants' previous health related discussions with family and friends. Here, the participants spoke about how sharing personal health related information in adulthood was not always helpful, sometimes unpredictable, and unresponsive in terms of others' reactions to their experiences. This was particularly evident in Jane's account of lay referral where she reflected upon a previous conversation with her sister who she had approached due to her sister's professional knowledge. Her sister's response appeared somewhat rejecting, unemotionally attuned which created increased anxiety for Jane. The family *'friction'* which Jane has previously talked about (see the above themes) is apparent below:

"... one of my sisters is ... she's done a lot of research on tropical medicine... so I question her a lot and she's um quite brutal... She will say... "Oh, well yes, you know, the muscles on your face are- have collapsed and they will continue to do so, so before long you will be dribbling." Like, you know, our Great Auntie... You know she used to spit at us... so I-I do have anxieties about that..."

(Jane)

In an attempt to cope with her bodily changes, Marie withdrew and avoided any health-related relational interactions; she expressed a sense of feeling misunderstood, rejection, and frustration from her husband. These feelings arose during previous attempts to discuss her bodily changes with friends and family which had exacerbated her negative emotions and relational avoidance:

"I'm trying not to be among people who are stressful. Avoid tension. Even my husband... cause he doesn't understand..... It's not me pretending it's there. This is the bit I've been really finding hard to-to get across, how to explain to these people. That is one of the worst nightmares..."

(Marie)

For Laura, learning who she can talk to (or who to avoid) about her health held significance. On occasions, Laura's family had seemed to reject and dismiss her experiences, which had clearly shaped who she talked to about her health:

"... I told her... I was being sick... but nothing more... 'cause I don't really talk about how I'm feeling... I've got generalised anxiety disorder but mental health is not talked about in my family... my husband and his... mum and sister, they've been through mental health so I talk to his family instead of mine. But if it's physical, I tend to talk to mine 'cause in my-my parents' house, mental health doesn't exist... she probably just say... "Stop feeling sorry for yourself," if I told her how I felt so (.) I don't bother. That's what the husband's for isn't it..."

(Laura)

The complexity of the participants' relationships is apparent and how these previous experiences have shaped how they made sense of lay referral.

Expression and Repression; Shaped Lay Referral

This sub-theme exemplified how the participants have learnt from past experience whether to engage or to avoid lay referral. For instance, Jane appeared dismissive of her own experiences and indicated that she would avoid lay referral (similar to her parent's behaviour and childhood experiences). However, Jane discussed how she has previously listened and talked to other people about their health, which offered her some form of emotional relief, distraction, and/or deflective experiential avoidance. The reader also gains a sense that Jane emotionally-regulates through providing this relational space for others which she is unable to gain from her close relationships:

"(.) I wouldn't say anything... People can't cope with their own problems...I don't see... any relief by telling somebody else... A lot of people ... tell me all their problems... their anxiety comes down and then my anxiety comes down... I can deflect any problems that I have away from me... I know that sounds a bit evil saying that..."

(Jane)

Similarly, Megan suggested that she would could not *'justify'* discussing her bodily changes unless she was seriously ill. Megan alludes to a sense of protecting others in order as to not *'worry'* them. For Megan, there was no *'point'* talking to her mother if her mother was going to tell her to go to the doctors as her partner already had:

"... when... you feel that the pain is not strong enough, you can't really justify telling people because why would be the point of telling them if you're just gonna worry them, if it's not... killing you?..... I didn't see the point of telling her that I had these pains if I knew she was gonna then tell me, "You have to go to a doctor now." I was then gonna say, "Ah, leave me alone." ...Which my partner had been saying forever, but who cares? ..."

(Megan)

Rather than avoiding lay referral altogether, Laura had learnt to approach different family members in reference to different health concerns. For example, she approaches her mother for advice in regards to alternative medicine for her physical bodily changes. Laura expressed how she *'trusts'* her mother's input which impacts her help-seeking behaviour. The process of lay referral in Laura's family does not take a healthcare professional route:

"...my mum and her sister are very into... alternative medicine... herbal things... if mum doesn't know something, she'll ask her sister and her sister will know all of the answers... they're not always correct... my mum trusts her, and I therefore trust my mum. And usually they work..."

(Laura)

Lay Referral; The Acquisition of Online Information

In this sub-theme *'lay referral; the acquisition of online information'* we see gaining online information as a coping response and as a modern form of lay referral which supported how they made sense of their bodily stimuli. For instance, Kay accessed information online at several points prior to attending the doctor and then again after the medical consultation. She described this as a process of exploration to help her make sense of her bodily changes and to aid her decision making:

“... I’m very careful about believing everything on Doctor Google... I try not to self-diagnose... I know I did self-diagnose because I thought all the symptoms were all there... They told me what blood test I needed... there was a whole battery of them so I went on Google... I looked at leukaemia... pernicious anaemia... I couldn’t decide... so (.) the doctor was the best person to do that.”

(Kay)

Faye’s experience of gathering information online was somewhat different from Kay, mainly grounded in Faye’s professional knowledge. Faye’s knowledge in combination with the information she sourced online offered reassurance and reinforced her own interpretation(s) of her bodily changes:

“I just googled it... I know that sounds awful... the NHS website and things like that... probably because I have a bit of knowledge myself... I, just know it goes away... it was reassuring ya... I have looked at a couple of papers... I would mostly go with the NHS information really, rather than people discussing it themselves...”

(Faye)

“I’m constantly on the lookout on the internet and, you know, on different forums and different things...”

(Jane)

The way in which the above participants’ sought information was not only with people but also online. Gaining information online offered an alternative way in which to make sense of their previous/ current bodily changes.

Theme Five: Divergent Help-Seeking Behaviour

The participants often held multiple interpretation(s) of their bodily changes, and differed with a variety of active or avoidant help-seeking behaviours. Help-seeking behaviour was influenced by the following factors: perception and, interpretation, emotion and the participants’ individual social and close relational experiences.

Active Help-Seeking and Consultation

'Active help-seeking and consultation' represents the participants who actively planned or have recently sought professional healthcare advice. What became apparent is that help-seeking behaviour involved multiple factors beyond that of simply arranging an appointment. For Marie, seeking healthcare professional advice was of great importance. Based upon her previous negative experiences of a consultation where she did not receive a medical diagnosis as expected, Marie expressed anxiety/ desperation and appeared unable and/ or unwilling to accept this lack of diagnosis which rendered her bodily changes as medically unexplained. Her almost hyperactivated help-seeking behaviour not only facilitated a renewal of her sick note but represented her emotional need to keep fighting for a medical diagnosis and recovery. Medical consultation has been an anxiety provoking event for Marie, compounded by her expectations of what the doctors will say (*'...it will go in time...'*) at a time when she already felt anxious:

"I'm going to see the doctor... 'Cause I have to-. I have to renew my sick note. I try and see him because I don't wanna lose that contact because I'm still not right... I'm not gonna accept this forever... That is what probably the doctor said, "This is what you've got and it will go in time." But when?... I need it done yesterday...."

(Marie)

Megan's description of a recent healthcare consultation conveyed a challenging relational process. She described how it was important for her to leave the consultation with the medical tests that she thought were needed. Megan described how she learnt to attend consultation, to *'get the most out of the GP'*. For Megan, it appeared that the opportunity for discussion was important. Megan distinctly outlined that for her, it is important to feel valued in the doctor-patient relationship and seen as *'intelligent'* as opposed to being dismissed *'into the group that has fish fingers on a daily basis'* by the doctor. Megan's perception of being *'lumped into'*, out grouped, or dismissed could lead to question if (or how) her previous relational healthcare experiences influenced her perception of consultation and how she wanted to be perceived (i.e., not being stupid):

“I tend to think that... before you even open your mouth, they’ve assumed that you are unhealthy. And stupid. So, I try to make them see that I am intelligent and that I do take care of my diet... Because otherwise, you just get lumped into the group that has fish fingers on a daily basis and takeaways...”

“... I had quite a clear idea of what I wanted from the GP. I think from experience, if you... don’t know what you want, most likely you will just get a bit of a five-minute chat... “Come back in six months” ... so I knew I wanted to have some tests done... you learn how to (.) get the most out of the GP... If (.) you start a conversation by explaining that you’ve given thought to coming then you are there after having been observing yourself for a few weeks (.) that you are intelligent, and that you can compare things and can (.) then mostly likely they will be more open to actually discussing with you more than just telling you...”

(Megan)

The process of ‘active help-seeking and consultation’ would appear to be influenced by multiple embodied relational experiences which are drawn upon as people reflect upon their experiences.

Avoidance and/ or Non-Consulting Behaviour

‘Avoidance and/ or non-consulting behaviour’ are concerned with the accounts of those participants who, following the recognition and interpretation of their ambiguous bodily changes, decided not to seek healthcare advice. For these participants’ (i.e., Laura), the influence of previous experience and anticipated experiential/ relational expectations was also salient. For example, Laura gathered information about possible treatment options in the event she did consult for medical advice which appeared to become a maladaptive behaviour. Laura’s fear of invasive medical procedures ignited a sense of experiential avoidance and further reinforced her intergenerational family patterns of not going to the doctors. As a result, she had decided not to access professional healthcare advice:

“...the piles that I’d had throughout pregnancy are now bigger but I don’t want to go to the doctors about it. It’s not necessarily embarrassment... I have a habit of googling everything... I know what to expect and I don’t want to do it... like the

procedure to get rid of them (.) might have to end up in hospital... So, I'd rather just live with it."

(Laura)

Faye also discussed not seeking healthcare advice unless she was advised to by a private healthcare professional. Faye's decision not to consult appeared to be based upon her previous experiences and her own professional knowledge:

"I'm not going to go to the GP again (.) unless the [healthcare professional] thinks I need an x-ray... I'm not sure there's much they can do..... I think... because I've been in healthcare and that I know (.) it's important to move about a bit... I suppose I think, it's my, it's up to me to keep myself as healthy as possible... I've been a [profession]... in my career and it's the [profession] messages that you want to give people (.) is to try and think about yourself..."

(Faye)

Through the above the role of previous relational experiences are clear and how these experiences shape help-seeking.

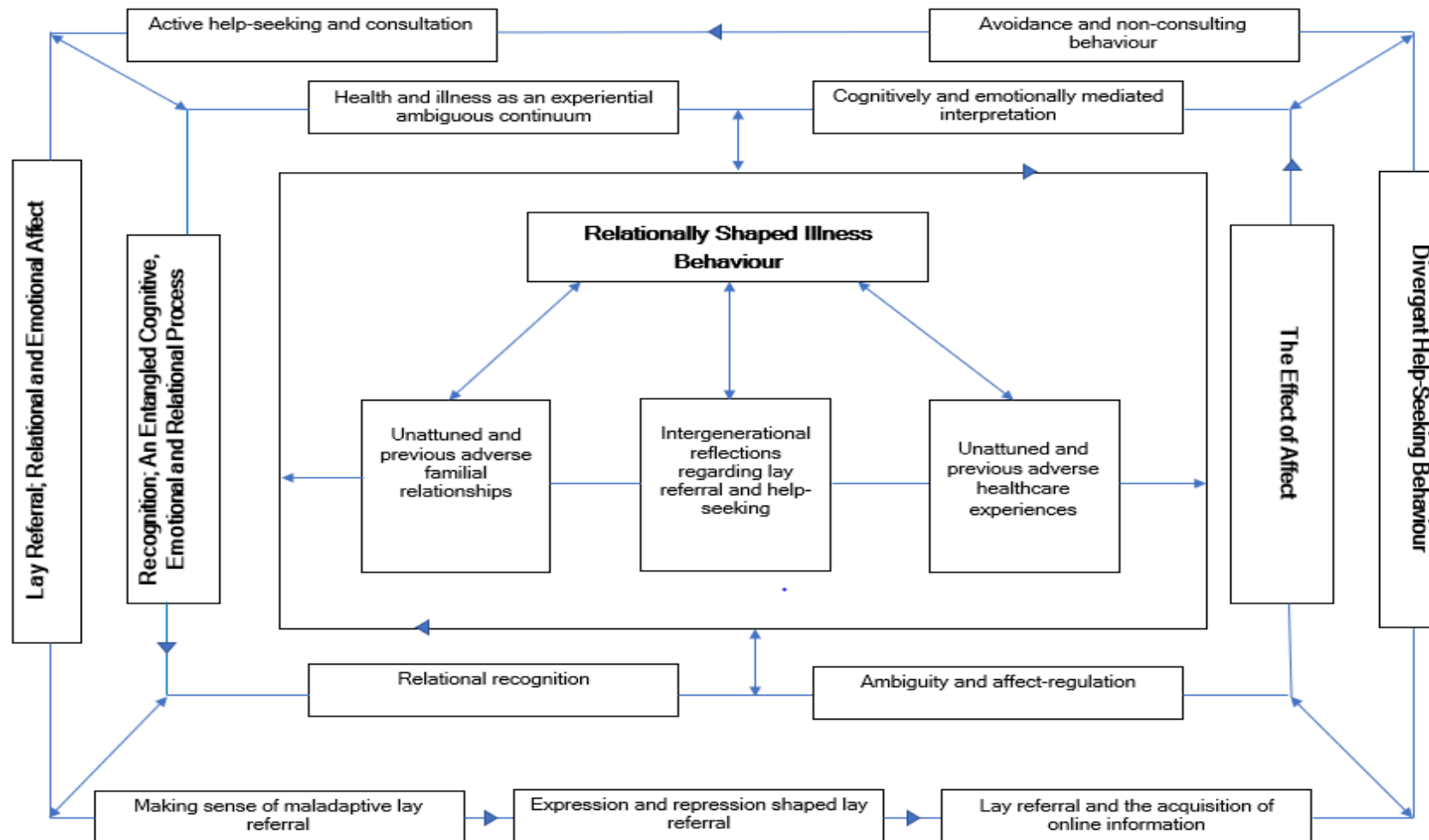
Discussion

The complexity of how the perception and interpretation of bodily changes as illness symptoms (or not) and the way in which this influenced the participants' emotional coping responses and the use of lay referral was explored. The participants' narratives were subject to an interpretative phenomenological analysis which examined the lived experience of bodily changes. The participants' narratives aligned with a psychological perspective of illness behaviour and provide unique insights into how people's cognitive, emotional, and/or behavioural responses have been temporally influenced through their prior interpersonal and relational experiences across the lifespan. The five main super-ordinate themes that arose as part of the analytical strategy are as follows; *'recognition; an entangled cognitive, emotional and relational process; 'the effect of affect'; 'relationally shaped illness behaviour'; 'lay referral; relational and emotional affect' and, 'divergent help-seeking behaviour'*. The below diagram (figure 4.3) maps the themes, expresses the multifaceted and interconnected nature of each of the super-ordinate main themes

(in bold) and sub-themes (non-bold). For instance, how '*relationally shaped illness behaviour*' at the centre links with both '*lay referral; relational and emotional affect*' and '*divergent help-seeking behaviour*' on the outside of the mapped themes. The rationale for presenting this visual map was to exemplify how each of the themes appear to connect whilst also holding value and meaning individually. The diagram is not intended to present a theoretical model nor to offer directional insight but instead aimed to collectively show how the themes could arguably shape each other. The themes are then discussed individually as to not lose the depth gained through this methodology. (The overall themes are also discussed in more detail as part of in Chapter six.)

Figure 4.3

A Visual Representation of how the Themes Interconnect



The main findings of this study will now be considered in more depth and in light of the existing literature and additional psychological theory beyond that which was outlined in the introduction. Additional literature has been drawn upon as an explanatory framework in which to consider what was important to the participants as part of their lived experience.

Theme One: Recognition; An Entangled Cognitive, Emotional and Relational Process

The super-ordinate theme of 'recognition; an entangled cognitive, emotional and relational process'; introduced the participants' perceptual recognition of ambiguous and inconsistent bodily changes that could not be labelled medically or identified as illness symptoms to the participants' knowledge or were not salient enough to cognitively represent typically known illness symptoms. The lived experience of bodily changes existed across a temporal experiential continuum of ambiguous, fleeting physical sensory, and emotional experiences, before the participant's more recent interpretation, emotional coping responses and lay referral. The sub-theme 'health and illness; an experiential ambiguous continuum' highlighted how the perceptual recognition of ambiguous, inconsistent bodily changes were often noticed through non persistent disruptions to daily activity, a spectrum of emotion due to the ambiguity of their experiences, or through changes in physical appearance. The challenges in terms of recognising, identifying, and labelling their bodily changes as illness symptoms were apparent across the participants' accounts and this is consistent with the Common- Sense Model of Self-Regulation (CSM) (Leventhal et al., 2016). Here, it could be argued that although the lived experience of ambiguous, fleeting stimuli and bodily changes were at times disruptive, they were not somatically severe enough, persistent, or disruptive enough to the 'normative self' to indicate illness nor to cognitively activate prototypes (illness-related memory structures) or generate mental representations of illness/ health threats (Leventhal et al., 2016). The ambiguity related to the experience of bodily changes and the consequent lack of activation in regards to the participants' cognitive illness schemas; for some, elicited negative affect, whilst for others, it resulted in them drawing upon changes in their physical appearance.

The relevance of the participants' social context and interpersonal interactions as part of the recognition process became apparent as several of the participants

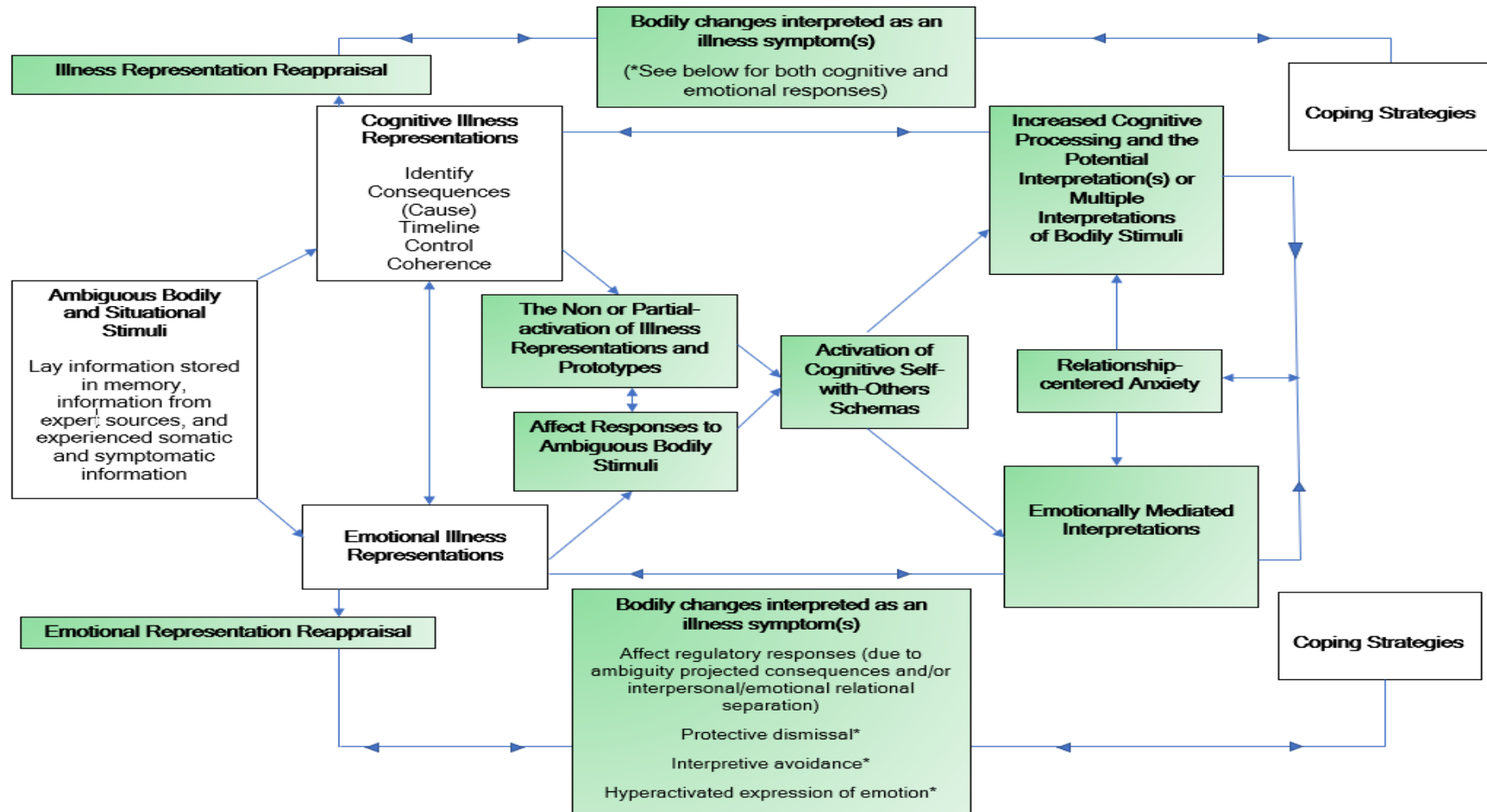
reflected upon their recent experiences of ambiguous bodily changes. These reflections included discussions around how the recognition of ambiguous bodily changes was not confined to physical sensations. Rather, their awareness increased through a lack of relatedness to their sense of 'normative self' (i.e., as a perfectionist) or relational self within their interpersonal space (e.g., at a performance level at work or recognised through expected communication norms with others) which heightened their experience of negative affect. The relational aspect of the participants' experiences demonstrates the temporal complexity of recognition when bodily changes are ambiguous and not salient enough to cognitively activate prototypes (illness representations) (Leventhal et al., 2016). Therefore, due to a lack of activated prototypes, it could be suggested that the participants drew upon their learnt patterns of relatedness, and socially acquired information to process, and evaluate their ambiguous, fleeting experiences. This aligns with the integrated theories of interpersonal cognition and in particular to the concept of relational schemas (i.e., Marie's experiences at work) with previous literature generally associated with depression, anxiety, self-esteem literature (Baldwin, 1994; 2005).

The inclusion of relational schemas in conjunction with illness schemas or prototypes as outlined in CSM enables the exploration of how self-with-other schemas facilitate additional cognitive/ attentional processing i.e., people's interpersonal experiences guide their attention, shapes perception, interpretation, and alternatively provides default information to help people make sense of ambiguous stimuli (Baldwin, 2005). Based upon the participants' narratives it would appear that these relational schemas (self/ other) redirected and increased the process of recognition in regards to their bodily changes through temporal self-evaluation in connection to other schemas (e.g., "I don't feel like me" / "you've lost your spark"; "I couldn't focus...I didn't want to make mistakes"/ "you need to go home"). For the participants in this study, the processing of ambiguous non salient bodily stimuli appeared to be different from how Suls et al. (1997) previously outlined the role of others from a social comparison perspective (the comparison of thoughts or opinions to assess if what they think is correct, as a form of values/ beliefs evaluation). In consequence, the theoretical integration of relational schemas (self-with-other) as part of CSM would offer an interesting perspective upon the role of temporally generated relational schemas in combination with cognitive and emotional processes in the context of ambiguous stimuli, symptom recognition, and appraisal.

The below (figure 4.4) offers a proposed adapted version of the CSM model (with coping strategies discussed later in the Chapter) in connection to symptom recognition based upon the finding of this study. Figure 4.3 proposes both the role and integration of non-activation (or partial) of illness representation, multiple interpretations, emotional representations, affect-regulation, self-with-other schemas, emotionally mediated interpretation, and relationship-centred anxiety (see theme three for more detail) in response to bodily stimuli. Overall, the below proposes an adapted version of CSM which encompasses a dynamic process. This dynamic process relates to when illness representations are not activated (or partially activated) but are cognitively and emotionally appraised and then reappraised as part of a feedback loop following the activation of relational self-with-other schemas which increases cognitive processing, relationship-centred anxiety and are emotionally mediated. Thus, the feedback loop based upon additional processing leads to the reappraisal of ambiguous bodily stimuli and the activation of different coping strategies (discussed as part of themes three, four, and five).

Figure 4.4

A Proposed Adapted Version of CSM in the Context of Ambiguous Symptom Recognition



* The green shading represents the novel concepts integrated into the CSM model as part of the findings of this thesis.

Theme Two: 'The Effect of Affect'

The super-ordinate theme of 'the effect of affect', described how the interpretation of bodily changes was often cognitively informed but also emotionally mediated; which due to the ambiguity of the participants' experiences increased affect-regulation. For instance, the sub-theme of 'cognitively and emotionally mediated interpretation' refers to how each of the participants brought interpretative meaning to the appraisal(s) of their ambiguous, inconsistent bodily changes. Interpretation was not only informed through their existing cognitive prototypes but became emotionally mediated through the meaning associated with the different appraisals (i.e. - menopause vs. anxiety and stress). It appeared that the participants faced difficulties around cognitively organising and evaluating non-salient stimuli. This difficulty, for some, lead to affect-regulatory responses such as emotionally protective dismissal and/ or interpretative avoidance, when prototypical meanings may have been associated with increased severity (potential chronic illness), projected life consequences (e.g., the perceived consequences of the menopause in reference to life stage) and a range of health threats. Here, the way in which the participants articulated their responses of not knowing and/or making the assumption that they were 'ok', supports the emotional coping processes outlined as part of the CSM (Hagger et al., 2017). In accordance with CSM if we understand the individual's lay perspective, and if their cognitive and emotional representations elicit fear, people may self-regulate through both cognitive and emotional avoidance coping strategies (Hagger et al., 2017). However, although CSM is a dynamic model and allows for reappraisal, what CSM does not account for is the role of affect-regulation (increased fear, panic, anxiety, sadness, and depression) elicited through the experience of interpersonal and relational uncertainty (i.e., separation from loved ones due to illness) when people experience ambiguous bodily stimuli. Therefore, to understand these interconnected processes and the emotions expressed by the participants adult attachment theory from an affect-regulation perspective and the concept of relationship-centred anxiety will be now considered (Feeney, as cited in Simpson & Rholes, 1998).

The findings of this study offer a novel way in which to understand how stress and anxiety created through relational uncertainty may elicit attachment behaviours or activate attachment systems during the experience of ambiguous health threats.

This appeared to be relevant, especially when ambiguous health threats created potential anticipated or projected physical or emotional separation. Bowlby (1969) outlined how attachment behaviours are likely to be elicited during threatening situations such as the experience of pain, fatigue, alarming events, and the absence or lack of proximity to attachment figures. This questioning if the participants' ambiguous health threats and interpersonal/ relational uncertainty, activated relationship-centred anxiety (anxiety derived from the absence or proximity with attachment figures) and attachment style behaviours (Feeney, as cited in Simpson & Rholes, 1998).

First, the role of relationship-centred anxiety in connection to the participants' narratives can be demonstrated through the expression of death related anxiety which may have created projected physical and emotional relational separation. Second, when people's perceptions were that other people may not believe their experiences (reject the health threat) this created a sense of emotional separation and increased the experience of relationship-centred anxiety. Other attachment behaviours are exemplified in this study through discourse related to self-reliance during episodes of illness (i.e.- characteristics potentially associated with avoidant styles) and/ or the increased hypervigilant expression of anxiety/ distress in terms of their experiences (Feeney, as cited in Simpson & Rholes, 1998). Therefore, although the participants discussed a range of different emotions and behaviours in response to the recognition and interpretation of their bodily changes, for some, they similarly expressed relational uncertainty and affect-regulation generated through their bodily changes. Consequently, self-with-other schemas and the concept of relationship-centred anxiety offer further explanatory value in terms of how these additional cognitive and emotional systems influence symptom recognition when people experience non-salient bodily stimuli.

This proposed integration of self-with-other schemas and the concept of relationship-centred anxiety as part of CSM in reference to symptom recognition is considered to be a novel expansion of the model. However, there has been some research (e.g., Vilchinsky et al., 2013) that has highlighted the role of illness perceptions in the context of attachment-related affect-regulation when people were recovering from cardiac illness. The longitudinal results found that illness perceptions mediated both attachment-related anxiety and anxiety symptoms. Therefore, although Vilchinsky et al. (2013) focused upon a specific medically diagnosed

cardiac illness (heart disease) which is likely to have activated the participants' illness representation, their findings indirectly support the proposed adaptations to CSM (figure 4.4) based on the results of this study. More specifically, Vilchinsky et al. (2013) found that activated illness perceptions mediated attachment-related affect systems, whereas, this study demonstrated non-activated or partially activated illness representations also activate attachment systems but in a different way. The difference in accordance with this study is that when illness representations are either not activated or only partially activated, symptom recognition and the interpretation of bodily stimuli may become emotionally mediated through self-with-other schemas, relationship-anxiety and in turn attachment-related affect-regulation. This indicates that attachment process not only relates to emotional or affect outcomes during illness recovery but hold an important role during symptom recognition when people experience non-salient bodily stimuli.

Theme Three: Relationally Shaped Illness Behaviour

The super-ordinate theme of 'relationally shaped illness behaviour' illuminated how the participants' previous temporal relational familial experiences had provided contextual insight to how they had learnt how and who to communicate with (or not) in regards to their own experiences of illness. For instance, the sub-theme of 'unattuned and adverse familial relationships' demonstrated how the participants' reflected upon a sense of relational difficulty, a lack of responsiveness, and challenge grounded within their close relationships and other family members' experiences of illness across the lifespan (i.e.- parental experiences of anorexia in childhood). It was through these sometimes longstanding unattuned inconsistent, rejecting, and/ or unpredictable responses within their family dynamics that the participants generally reflected upon their surrounding family norms and how they learnt to interact within their adult relationships. This highlighted how people's previous embodied relational experiences can also shape their later relational interactions, thoughts, emotions and potentially provide a cognitive script of expectations (Duschinsky, 2021). Consequently, the participants' narratives provided empirical support for a social-cognitive perspective (see the above and Chapter one). However, given the participants' lived experiences, the theories outlined under a social cognitive umbrella as discussed, do not necessarily capture the experiential essence of the findings of this study. For this reason, several other integrated

psychological theories associated with interpersonal cognition are explored (Baldwin, 2005) below. The relevance of these integrated theories is explained below, although it is recognised that they have not been applied in the context of physical health before, did not arise as part of the literature review in Chapter one nor as part of the scoping review in Chapter three. Another point for consideration is that it would also appear that there is a lack of research in relation to interpersonal cognition since the early to mid-2000s.

The advantage of an integrated theoretical approach, and the application of interpersonal cognition to the findings of this study is that we can account for the interactive nature between the self and other; in a unique way in terms of how illness behaviour is cognitively embodied, emotionally, and relationally shaped (Baldwin, 2005). For example, Andersen and Chen (2002) discussed the relational self based upon the assumption that previous knowledge provides a foundation for people to make sense of their present experiences and how past relational experiences are embodied as a self-other relationship in terms of mental representations. (This does not only relate to this theme but may provide a foundation across the others as well in terms of coping and help-seeking as discussed later in the Chapter.)

The relational self was theoretically formulated on multiple social-cognitive processes. These social-cognitive processes incorporated influential dyadic relationships, embodied mental representations of significant others, transference (when people's mental representations of significant others are activated during interactions with other people, which shapes their interpretation, emotional and behavioural responses); and how people relate to others, which becomes stored within memory processes (i.e. see Andersen et al., 1997; Chen et al., 2006 in terms of how these concepts interconnect). The conceptualisation of the relational self in turn proposes that these embodied social-cognitive processes influence people's patterns of interpersonal interactions, and behavioural tendencies etc. and is discussed in the context of this study below (Andersen & Chen, 2002; Chen, Boucher, Andersen & Saribay as cited in Simpson & Campbell, 2013). Albeit, following a search for additional literature it would appear that the concept of the relational self has seen minimal conceptual development (post the early to mid-2000s) although cognition has been recognised previously as a highly embodied or situated activity in the interpretative phenomenological literature (Larkin et al., 2011).

The theoretical relevance of the embodied relational self in the context of this study can be further witnessed through the sub-theme of 'intergenerational reflections; lay referral and help-seeking'. For instance, several participants discussed inherited and/ or embodied intergenerational family norms which narratively provided insight to several temporal reflective similarities between the way in which the participants described how their family previously talked about (or did not) illness in childhood and how they recently expressed (or did not) their illness experiences within their present adult relationships. Some participants articulated comparable emotional experiences of being dismissed in childhood during episodes of illness which were discussed and potentially re-experienced in their more current adult relationships when they experienced bodily changes. This led some to talk about why they avoided health conversations and lay referral in a learnt attempt to manage their close relationships or because of a cognitively scripted anticipated lack of sympathy and empathy from significant others towards their experiences. The cognitively, emotionally, and relationally entangled nature of the participants' narratives is in alignment with theories of interpersonal cognition and the relational self (Andersen & Chen, 2002; Chen, Boucher, Andersen & Saribay as cited in Simpson & Campbell, 2013). This exemplified not only the importance of social-cognitive process, and the embodied relational self but also the influential impact of previous relational experiences which may lead to script like expectations of others (Duschinsky, 2021). Especially in the context of how these experiences shape cognitive relational schemas and mental representations of significant others (people's cognitive structures that represent interpersonal patterns of social relatedness and interactions with others) (Baldwin, 1995; Andersen et al., 1997). The findings of this study present a unique insight into the embodied or cognitively scripted nature of illness behaviour. Illness behaviour is in consequence proposed to be an embodied relational social- cognitive process when people's generalised relational mental representations or schemas (based upon their relationships and closeness with significant others across the life span) are activated during their more present interpersonal health interactions. These interpersonal health interactions are proposed to include active engagement with lay referral and professional healthcare help-seeking but also deactivation resulting in relational avoidance. The deactivation and relational avoidance of lay referral and help-seeking is thought to arise when

negative consequences are anticipated based on previous negative relational interactions (Andersen & Chen, 2002; Chen et al., 2006).

Another important finding was the sub-theme of 'unattuned and previous adverse healthcare experiences'. Here, the relevance of relational schemas based upon the previous experience of healthcare services and interactions with healthcare professionals arose. For some participants, previous help-seeking behaviour had resulted in difficult and challenging relational interactions with healthcare professionals; with the participants often alluding to a sense of relational adversity and experiential unresponsiveness in the patient-doctor relationship. The participants frequently articulated how their individual needs (physical, emotional, and/ or relational) went unmet, which indicated that their help-seeking behaviour became maladaptive and reinforced their negative beliefs and relational perceptions, and increased a lack of trust in the relationship.

Interestingly, this finding has also arose in Salaheddin and Mason's (2016) general practice research, which explored why young adults may choose not to gain support when they encounter an emotional or mental health difficulty. The study involved a mixed methods cross-sectional online survey (N=45) and concluded that young adults may find it challenging to access support from others, given negative perceptions about mental health and help-seeking itself. The relational perceptions of participants in this study related not only to close others but to wider relationships which may influence illness behaviour, lay referral, and help-seeking. This finding aligns with Andersen and Saribay (as cited in Baldwin, 2005) who outlined the relevance of attachment theory in connection to the relational self. For instance, the theoretical assumption of attachment theory is that through early interactions with others (i.e., family members), children develop cognitive and relational schemas and models of self and others which endure into adulthood. These relational schemas influence behaviour and regulate affect, people's beliefs, perceptions (negative and positive), and/or expectations of other people in a theoretically compatible way as the model of the relational self (Andersen & Saribay, 2005). However, attachment theory moves beyond the model of the relational self in isolation and outlines several conceptual differences as to the way in which these enduring schemas and how attachment patterns influence personal adjustment and the experience of adult relationships (Simpson & Rholes, 1998). For example, attachment theory suggests that the experience of responsive caregiving in the past (i.e. during childhood) is

more likely to lead to a secure attachment in adulthood which influences seeking of advice during times of threat. For instance, secure attachment refers to when people trust, feel comfortable with close interpersonal relations, and express relationship satisfaction (Hazan & Shaver, 1994; Mikulincer & Shaver, 2020). In contrast, an insecure attachment style may develop in response to inconsistent or/and unresponsive caregiving, and the experience of this may elicit feelings of relational anxiety and/or discomfort and relationship dissatisfaction during adulthood (Hazan & Shaver, 1994; McWilliams & Bailey, 2010). Therefore, when considering embodied relational schema development, attachment theory may offer an explanatory framework that accounts for why some of the participants expressed negative, unresponsive, and difficult interpersonal relationships with significant others which were also expressed and narratively reflected their potential script expectations in regards to lay referral, help-seeking and their adulthood perceptions of healthcare professionals.

Theme Four: Lay Referral; Relational and Emotional Affect

The fourth super-ordinate theme of 'lay referral; relational and emotional affect' uncovered how the participants made sense of past health conversations and lay referral in their adulthood. The sub-theme of 'making sense of maladaptive lay referral' outlined how previous experiences of sharing personal health related information in adulthood was not always helpful and maladaptive when close others were not responsive, rejected, or dismissed the participants' health related experiences. This often led to increased negative affect and, for some, discussions around avoidance of interpersonal health communication and lay referral. The use of qualitative methods in this study illuminates how the lived experience of lay referral is not just a directional process (to go to the doctors or not to go) but a complex embodied, scripted cognitive, emotional, and relational interaction. In turn, the findings of this study move beyond the previous conceptualisation of lay referral (i.e., Freidson, 1970) and offer an alternative perspective in connection to the previously discussed health psychology theories which incorporated lay referral, and social comparison theory, etc. (Leventhal et al., 1992; Suls et al., 1997). For example, the participants discussed previous attempts to seek proximity or to avoid lay referral within their close relationships (parents/ partners/ adult siblings) in light of their past health threats and past relational experiences. Lay referral as described by the

participants often appeared to be unattuned, did not meet their needs, felt like an insensitive process in which some were dismissed by others increased negative affect and relationship-centred anxiety.

A useful way in which to understand how people retrospectively made sense of lay referral is through an alternative aspect of attachment theory (different from that outlined above as part of the symptom recognition process). This alternative aspect of attachment theory is when close others are perceived as insensitive (based upon their mental representations) which can result in insecurity. Insecurity in combination with appraised threats can elicit further increased negative affect as the relational space is appraised as unsafe. Therefore, if the appraisal of seeking proximity with others (lay referral) when under threat is not likely to ease distress or support adjustment (i.e., emotionally) people may encounter attachment-deactivating strategies based upon their cognitive scripted expectations. Deactivating strategies may result in people distancing themselves from others and may lead to relational avoidance in order to protect themselves from increased negative affect. Hence, it could be argued that when attachment systems are activated through previous health threats, the participants either learnt to affect-regulate and avoid (attachment-deactivating strategies) certain individuals who were insufficiently responsive; or they sought proximity to people they trusted, who supported personal and social adjustment to the threat (Mikulincer & Shaver, as cited in Baldwin, 2005; Mikulincer & Shaver, 2009).

The relevance of attachment systems to lay referral is further exemplified through the sub-theme of 'expression and repression; shaped lay referral' (Mikulincer & Shaver, 2009). Here, some of the participants spoke about recently engaging with those they trusted within lay referral; whilst others talked about recent attempts to avoid lay referral with those participants dismissing their own experiences and dismissed any form of positive benefits in terms of lay referral. This is consistent with attachment theory that suggests that if people appraise proximity seeking as unhelpful in terms of reducing distress, as part of the deactivation process people distance themselves; become dismissive in terms of the threat, suppress thoughts, emotions and consequently, people express self-reliant attitudes and reduce their need for support from others. This perceived reduced need for relational support from close others when previous interactions have not supported adjustment can be witnessed within some of the participants' recent accounts in connection to lay

referral. These accounts exemplify how people can affect-regulate and reduce negative affect through not only engagement but disengagement with lay referral. This indicates that attachment related regulatory processes in the context of lay referral do not necessarily reflect only how people rely on close relations to reduce distress but instead people can affect-regulate through avoidance of close others.

The self-reliant nature of participants' illness behaviour was evident as part of the sub-theme 'lay referral; the acquisition of online information'. The acquisition of information online in reference to their ambiguous bodily changes (i.e.- leukaemia vs. pernicious anaemia) offered an accessible and available safe space to engage with problem-focused coping. This online problem-focused coping strategy could arguably have been activated through stress concerning the experience of ambiguous bodily changes and deactivating attachment strategies to affect-regulate, removed the interpersonal, relational affect aspects of lay referral, and led to relational avoidance. As discussed in the introduction of this Chapter, Hagger et al. (2017) encompassed instrumental, problem-focused coping (when people seek to gain advice or information) and emotion-focused coping (when people seek moral support, understanding, and/ or sympathy) within a generic concept of 'seeking social support' as part of CSM. However, although it would appear that lay referral in the context of this study's findings could be thought of as social support, it is also argued that the more generic concept of social support outlined in CSM does not capture the complexity of cognitive- or affect- regulation processes which are activated through ambiguous bodily stimuli. This lack of ambiguous illness specific threat can also be exemplified through the social support literature that has not explored this process in the context of symptom recognition. Rather, the findings of this study indicate that not only an appraisal of illness perceptions takes place but a cognitive appraisal/ reappraisal of lay referral (based upon relational schemas) in connection to ambiguous health threats (as outlined in the sub-theme 'making sense of maladaptive lay referral'). For instance, Florian et al., (1995) examined the effects of attachment style on the perception and search for social support. Findings demonstrated that secure individuals perceived and sought higher levels of emotional and instrument support from others than those who self-reported avoidant attachment styles. Although useful, this again arguably does not capture the complexity of these processes when people experience ambiguous, fleeting bodily stimuli during symptom recognition and coping.

In order to capture what was important to the participants the following relational conceptualisation of lay referral is proposed from an attachment theory perspective. The below conceptualisation (Figure 4.5) proposes a dynamic process and/ or coping strategy that moves beyond generic seeking of social support. Figure 4.5, alternatively outlines lay referral which has been conceptualised (based upon the results of this study) to involve not only the appraisal/ reappraisal of illness perceptions but a relational appraisal. This relational appraisal is based upon scripted expectations of lay referral and how this may elicit relational-affect (i.e., increased negative affect or a sense of safety/ adjustment) in terms of the anticipated lay referees' responses to their potential engagement with lay referral. Therefore, figure 4.5 theoretically encompasses the embodied relational-self (see theme three), adult attachment style, and the appraisal of lay referral and illness/ emotional representations based upon a feedback loop system. This is proposed to expand our understanding of lay referral and the interconnected process between the individual and the lay referee and suggests an additional aspect of the coping strategies outlined in CSM.

Theme Five: Divergent Help-Seeking Behaviour

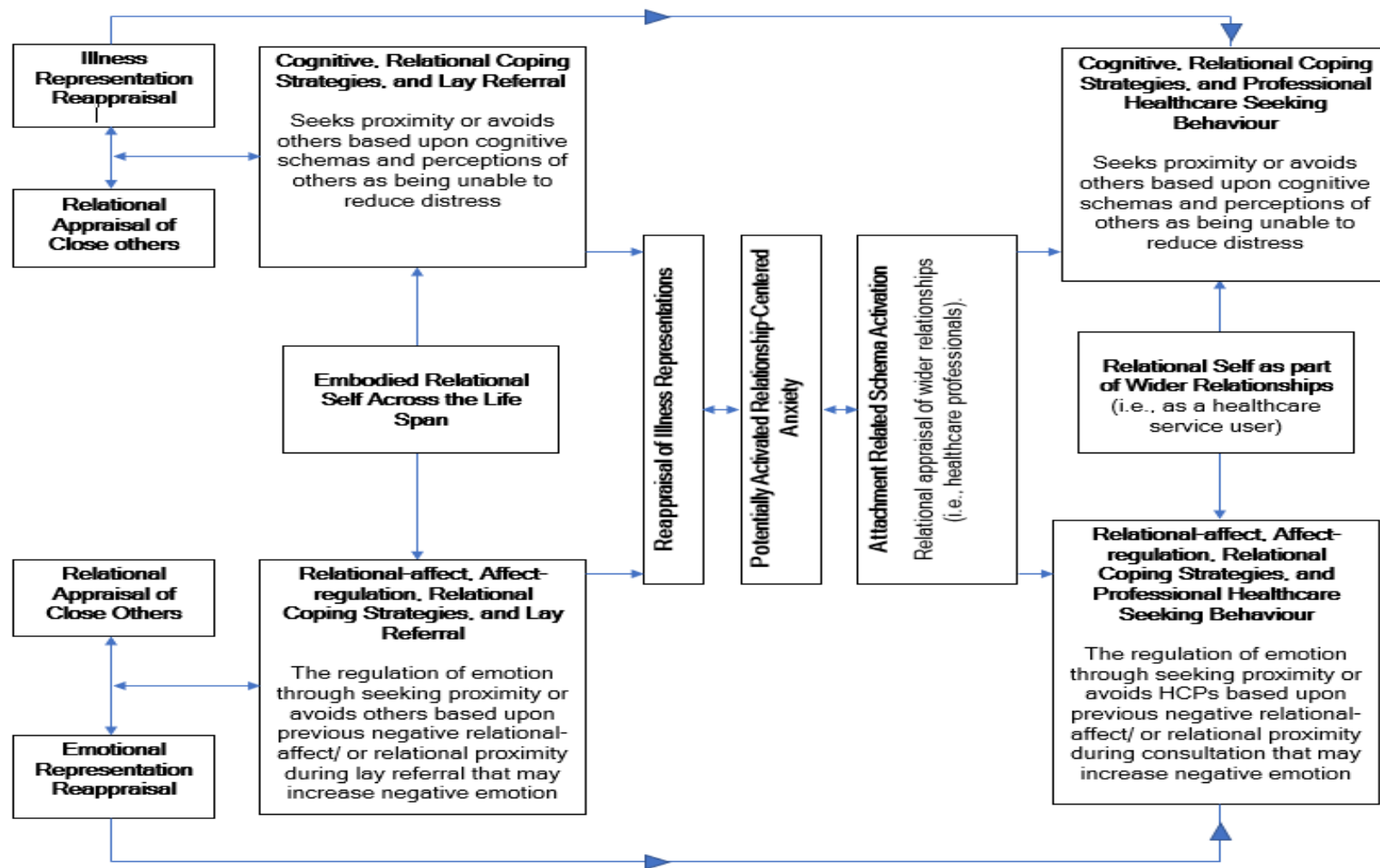
The final theme introduced the participants' help-seeking behaviour in the context of gaining healthcare professional advice in response to their bodily changes. The participants often held multiple interpretations, discussed a variation of coping responses, and a range of active or avoidant health service help-seeking behaviours. The divergent nature of help-seeking found as part of this study offered an idiographic insight that moved beyond the historical perspectives of illness behaviour and utilization behaviour (Anderson, 1973; McKinlay, 1972; Safer, 1979; Zola, 1966). This was exemplified through the different sub-themes of 'active help-seeking and consultation' and 'avoidance and/ or non-consulting behaviour'. Here, the complexity of actively seeking healthcare advice was demonstrated, especially when the participants had encountered previous ineffective and unhelpful healthcare consultations. From an attachment theory perspective Mikulincer and Shaver (2020) it could be argued that the experience of seeking healthcare advice against the backdrop of embodied previous negative experiences and more recent ambiguous health threats may have activated the participants' relational schemas, attachment behaviours, and strategies. For example, the participants expressed a focus upon the appraised relational aspects of help-seeking and relational communication. At times this related to the simultaneous need for contact with healthcare professionals (proximity) and a sense of increased anxiety (relationship-centred anxiety) when healthcare professionals were appraised as discouraging or not responsive in terms of a diagnosis etc. Another example could be the increased expression of self-reliance and how for some they had learnt to manage consultation to meet their individual needs.

Similarly, discourse related to avoidant help-seeking behaviours was also grounded within previous negative experiences and on occasion related to fear. This indicated that those who appraised seeking healthcare as very unhelpful, ineffective, anxiety-provoking, or something to be fearful of, affect-regulated through physical/ emotional distancing and avoidant behaviours/ deactivating strategies. This deactivation of help-seeking, in consequence, removed the potential risk of feeling rejected (unheard by professionals or their health needs being left unresolved based on previous experience) and also removed any insensitive interpersonal interactions during consultation, in response to their ambiguous, fleeting bodily changes which

did not represent classically known illness symptoms. Through the above, the importance of previous patient-doctor interpersonal processes, relationships, and attachment theory is evident. These findings are supported by previous research, for example, Morris and colleagues (Morris et al., 2009) who explored whether attachment style influenced the quality of alliance between diabetes service users and healthcare professionals. From a sample of 48 service users, the results indicated that avoidant attachment was significantly associated with difficulties in the therapeutic alliance. This reinforces how different aspects of attachment theory could be applied to different processes across the time frame between symptom recognition and help-seeking. To capture the experiential and relational aspects of the participants' narratives the below concept in terms of lay referral and help-seeking has been developed (figure 4.6). Figure 4.6 offers a proposed way in which to consider these processes through a relational lens. This was an important aspect of this study as Mikulincer & Shaver (2020) indicated that the broader application of attachment theory could be drawn upon to explain psychological functioning as part of these wider relationships although no previous literature has explored this.

Figure 4.6

The Proposed Role of Attachment, the Relational Self and Professional Healthcare-Seeking



Conclusion

This study has explored how the perception and interpretation of bodily changes influenced the participants' emotional coping responses and the use of lay referral. First, the perception of ambiguous, fleeting bodily changes appeared to draw upon relational/ self-with-other schemas as a source of self-evaluation and additional attentional processing when the stimuli were not salient enough to activate illness prototypes and created negative affect. Second, the participants often faced difficulty cognitively organising and evaluating non-salient stimuli which lead to affect-regulatory processes (protective dismissal or avoidance) when their bodily changes could be appraised to represent different meanings associated with increased health threats and illness severity. The experiential ambiguity of the participants' health threats sometimes led to a sense of interpersonal uncertainty, relational anxiety, and potential projected separation from close others. Third, the participant data uncovered the complexity of illness behaviour, which appeared to be an interactive process influenced through previous experiences across the life span and a range of scripted cognitive, emotional, and relational factors. Therefore, to explain these processes this study took an integrated theoretical approach, moving beyond traditional approaches that encompassed CSM, theories of interpersonal cognition, and attachment theory. Fourth, the lived experience of lay referral illuminated how this process is shaped and scripted cognitively through previous relational experiences across the life span and affect-regulation. For example, the participants often learnt through previous interactions with family members and close others to appraise if lay referral was a process to seek (if the other person would be available/ responsive to support adjustment) or avoid (unavailable/ unresponsive) in adulthood which on occasion led to self-dismissal/ repression, the increased expression of self-reliance, and problem-focused coping. Finally, the divergent nature of help-seeking arose which further highlighted the complexity of illness behaviour based upon previous negative, unhelpful and ineffective healthcare related interpersonal experiences. For some, they actively had or were going to gain healthcare care advice which elicited different cognitive, emotional, and behavioural responses (anxiety, dismissiveness); whilst for others, they avoided seeking healthcare professional advice in order to cope and affect-regulate on their own. Overall, the findings of this study indicated the significant role of interpersonal

cognition, the relational self, relational schemas, attachment behaviours, and affect-regulation when people experience ambiguous bodily changes. Therefore, when considering each of the individual themes it is also apparent how they interlink, with cognition, emotion, and relational factors all interconnecting and shaping different aspect of the time frame between symptom recognition and help-seeking behaviour. Based upon this the adapted version of the CSM in terms of symptom recognition, lay referral, and professional healthcare seeking could also be integrated with the Model of Pathways to Treatment (Scott et al., 2013) (as discussed as part of Chapter one).

Future Research

Based upon the findings of this study and to build upon previous literature, a mixed and multi-methods study is proposed. It is suggested that the illness perceptions and the perception of potential health threats in connection to bodily changes are investigated in relation to the different adult attachment styles, lay referral and help-seeking behaviour. This would provide an opportunity to explore symptom recognition in the context of bodily changes and how or if adult attachment style shapes lay referral and professional healthcare seeking behaviour. In terms of suggested applied implications from this study see Chapter six.

Chapter Five

A Relational Perspective to Illness Cognition, Emotional Coping Responses and Lay Referral; A Concurrent Triangulation, Mixed and Multi-Methods Design

Introduction

Coronavirus, Bodily Changes, and Illness Perceptions

Severe Acute Respiratory Syndrome Coronavirus 2 (SARS-CoV-2) is the coronavirus that causes Corona Virus Disease (COVID-19), a disease whereby most of those infected experience mild to moderate symptoms (i.e., a high temperature, dry cough, tiredness, a loss or change to a sense of smell or taste and/or a new, continuous cough) (WHO, 2021). Other less common symptoms are aches, pains, sore throat, diarrhoea, and headaches; whilst more serious symptoms include difficulties breathing, shortness of breath, chest pain, and chest pressure (WHO, 2021). These symptoms overlap with other common conditions and respiratory illnesses such as influenza (flu) although differences also exist concerning the spread, severity, incubation period, and how long people may be contagious (Centres for Disease Control and Prevention, 2021). In the context of a worldwide pandemic understanding the similarities between other illness conditions and COVID-19 illness symptoms is an important area of research as it could provide insight into how people make sense, interpret, respond and cope with any bodily changes, including which could be not COVID-19, but potentially cancerous symptoms.

The topic of illness perceptions has previously been explored within psychological theories such as the Common-Sense Model of Self-Regulation of illness (CSM) (Leventhal et al., 1992). The CSM proposes that individuals make sense of their bodily changes from their common-sense understanding of the symptoms they attach to certain illnesses. This common-sense 'lay model' of understanding derives from the individual's knowledge following direct or vicarious previous experiences of illness(es) embedded within different social contexts and is influenced by individual differences associated with a range of personal factors. These personal factors include (but are not exclusive to) gender socialization and life stage. Bandura (1999) outlined the social cognitive theory of gender role development (how males and females as children become socialised into feminine and masculine adults) and how gender influences motivational and self-regulatory mechanisms such as behavioural and emotional regulation. For instance, Queenan et al. (2017) conducted a study to explore the appraisal of symptoms, help-seeking,

and, lay consultation The results in connection to gender suggested that men may have been less likely to tell someone about their symptoms compared to women. Queenan et al. (2017) attributed this to factors around perceptions of masculinity. In consequence, personal factors in potential conjunction with the individual's knowledge and experience may generate cognitive schema or 'illness schematics' (e.g., perceptions of what 'flu' is; 'what cancer is') stored within memory, which subsequent symptom stimuli may then activate. These perceptions, referred to as 'illness representations' enter a dual-parallel processing system that incorporates objective symptomatology ('I have a fever'), subjective cognition ('I think this is flu'), and emotional responses ('I am worried'); lay representations then activate symptom appraisal and coping responses ('I need to self-medicate', etc.) to manage illness threat (Aujla et al., 2016). This self-regulatory system subsequently influences people's functional state, or other outcomes such as emotional distress and can lead to a variety of coping responses (i.e.- emotional distress or fear induced through bodily changes or symptoms that may represent a life threatening illness could activate avoidant coping responses) (Hagger et al., 2017). Coping responses are then appraised in terms of treatment/ plans which are cognitively feedback with regards to if the threat is progressing or if coping responses are not working which may, in turn, alter illness representations. CSM has been developed over 50 years and is widely considered to be a dynamic model (Leventhal et al., 2016).

The role of illness perceptions regarding potentially life-threatening illnesses, in terms of coping and adjustment can be seen in Hopman and Rijken (2015) where cancer patients' illness perceptions, illness characteristics, and coping responses were explored. The study involved a sample of 325 cancer patients who completed the Dutch version of the Illness Perception Questionnaire and The Mental Adjustment to Cancer (Hopman & Rijken, 2015). Findings indicated that patients' perceptions varied in terms of the chronicity of their cancer but overall, they believed that the illness would be long lasting. For those who experienced skin cancer, they perceived lower perceived consequences, whereas those who had more recently undergone treatment perceived higher consequences and that their illness was more chronic. Hopman and Rijken (2015) concluded that people may benefit from support to reduce the perceived threat of their illness as opposed to increasing people's perceived beliefs about control over their illness.

More recently given the outbreak of the COVID-19 pandemic, research has also sought to understand how lay representations influence adherence to precautionary behavioural measures outlined in government policy from an illness perceptions perspective. For example, Chong et al., (2020) investigated illness perceptions during the second wave of COVID-19 in Hong Kong between April and June 2020, with data collected in reference to people's illness perceptions, coping, and self-efficacy and their adherence to precautionary measures (physical distancing, limiting travel, washing hands, etc.). A sample of 514 participants took part in the cross-sectional online study. The results indicated that COVID-19 illness perceptions had a significant influence on adherence to precautionary measures, which held implications in terms of effective public health interventions to address avoidance-based coping and precautionary self-efficacy. This was an important study in response to the COVID-19 pandemic, although only one participant out of the 514 reported that they had experienced the COVID-19 virus during this period. It could therefore be suggested that research is needed to explore people's illness perceptions, cognitive and emotional representations of bodily changes when bodily stimuli represent less or more of a health threat. Given how COVID-19 symptoms may involve symptoms that could be associated with and other common conditions in terms of their symptom labels (i.e. -flu, colds, coughs); research could focus on the extent to which the shaped nature of people's illness schemas and emotional representations may or may not activate in response to differing levels of health threat. Data collected in the context of a world pandemic would extend our understanding of these processes during COVID-19.

Lay Referral and the Potential Impact of Coronavirus

In addition to the precautionary measures described above, other physical restrictions have been in place during the COVID-19 pandemic in order to reduce the potential spread of COVID-19. These other physical restrictions include social distancing, quarantine, and/ or self-isolation (Centres for Disease Control and Prevention, 2021). Research conducted before the COVID-19 pandemic has identified how the experience of loneliness and the perception of poor social support may negatively influence people's physical and/or mental health symptoms, recovery, and social functioning (Wang et al., 2018). This is likely to be relevant during the COVID-19 pandemic when people may experience increased social

restrictions which reduce their ability to interact with others. One area for exploration could be people's perceptions of lay referral at an individual level and who people engage with (or not) when they discuss their bodily changes before potentially seeking healthcare professional advice. This alternative way of considering lay referral, (as opposed to the traditional approach at a societal level) (Freidson, 1970; Zola, 1973) and building upon the findings of Chapters three/ four would give insight into how the COVID-19 pandemic has impacted these relational processes.

Coronavirus and Attachment Theory

Attachment theory (Bowlby, 1997) derives from developmental and social psychology research to explain a range of human behaviours (e.g. relational interactions). The theoretical assumption is that through early interactions with caregivers (i.e., family members/ parents/ guardians) children develop cognitive and relational schemas which endure into adulthood and which influence behaviour and regulate affect, beliefs, and/or expectations of others in their close relationships. Attachment theory advocates that responsive caregiving is more likely to lead to an adult secure attachment which is seen as occurring when people trust, feel comfortable with close interpersonal relations, express relationship satisfaction, and a willingness to depend on other people for support (Hazan & Shaver, 1994). In contrast, an insecure attachment style may develop in response to inconsistent or/and unresponsive caregiving, and the experience of this may elicit feelings of relational anxiety and/or discomfort in personal close relationships, the expression of relationship dissatisfaction and conflict (Hazan & Shaver, 1994; McWilliams & Bailey, 2010). More recently than the traditional attachment theory research, it has been applied to the field of health and illness research (McWilliams & Bailey, 2010), and has generally been based upon its evolutionary position i.e. that infants maintain proximity to caregivers (typically parents) during times of threat (Roisman, 2007). Attachment theory offers an additional perspective to the examination of health-related behaviours in the relational, cognitive and affect-regulation context (Feeney, 1994; Vilchinsky et al., 2013).

Two main methodological approaches to exploring attachment theory that assess attachment and categorise attachment styles differently are detailed in the literature: the first is observational research which has been conducted from a developmental perspective focused primarily on young people; the second adopts a

social psychology approach examined attachment dynamics in connection with close adult relationships (Fraley & Shaver, 2008). The developmental approach encompasses an Adult Attachment Interview (AAI) which assesses people's ability to communicate about their experiences with their attachment figure in childhood and caregiving. This traditionally involves a scoring procedure in reference to people's narratives that focuses upon attachment related language differences (amongst other factors) as opposed to people's attachment history (Duschinsky, 2020). In contrast, the social psychological approach typically employs quantitative self-report measures such as The Experiences in Close Relationship Scale (ECR) (Brennan et al., 1998) which examines people's beliefs about their close adult relationships informed through attachment patterns (i.e.- measured across two dimensions: anxiety and avoidance in connection to closeness with others), and attachment styles secure, preoccupied, dismissing and fearful-avoidant). The underpinning assumption of the second approach is that self-report measures generate participant responses that reflect cognitive schemas with regards to beliefs about the availability of a secure base within adult relationships (Duschinsky, 2020). Self-report measures are viewed as helpful to explore interpersonal interactions (relational and personal functioning), motivational systems, and attachment behavioural systems that give rise to caregiving, responsiveness, and support. For example, underpinning each of the four different self-reported adult attachment styles are two dimensions. These two dimensions are 'anxiety' and 'avoidance' in the context of the quantitative ECR scale although also outlined as the model of self and model of others by Bartholomew's (1990) as part of a four-category model. Therefore, the above exemplifies how different approaches, methods, data collection, and analytical strategies provide differing ways of exploring adult attachment; whether this be through people's qualitative orientated narratives or quantitative self-reported measures. In consequence, it is apparent that both approaches hold value, and that adult attachment style is considered important when exploring people's cognitive representations in regards to their beliefs, expectations, thoughts, and behaviours in the context of their social relationships (Fraley & Shaver, 2008).

Therefore, the relevance of attachment theory in the context of potential health threats during COVID-19 and the implications of physical restrictions upon proximity to close others is an emergent area of research. For example, Rajkumar (2020) published a narrative review that explored attachment theory and

psychological responses to the COVID-19 pandemic. As part the review, it was found that symptoms of anxiety and depression were most commonly collectively reported in the literature (Qiu, et al., 2020; Wang, et al. 2020 as cited in Rajkumar, 2020) in response to the COVID-19 outbreak. This suggested that these symptoms may reflect an integral aspect of human response to the potential (actual/ threatened) separation from people's attachment figures. However, the findings of this review are restricted to research published during the early stages of the COVID-19 and consequently only represent this time period. Another, potential limitation of this review is based upon methods of a narrative review itself, as the paper does not outline a methods section in which the reader can gain more information about the inclusion process. The role of attachment theory has been further reinforced by the research of Moccia et al. (2020) who examined how attachment style and affective temperament may influence the psychosocial impact of COVID-19 in an Italian population. Here, 500 participants took part in an online survey over four days which collected data in reference to sociodemographic, lock-down-related information, distress, temperament, and attachment style. Overall, the study found that people may have experienced distress and claimed that attachment/ temperament may influence mental health burden. The authors outlined that the study lacks longitudinal data to infer causality and in terms of limitations data collection again was situated in the earlier stages of the pandemic.

Bodily Changes, Lay Referral and Attachment Theory

The experience of bodily changes, symptom recognition, emotional coping responses, and lay referral whilst not in non-pandemic circumstances was explored in the IPA study. The themes generated as part of the IPA were discussed in much detail in Chapter four and considered in the context of an integrated theoretical framework which included theories associated with interpersonal cognition, the relational self, adult attachment theory, and the CSM. This novel integrated framework offered insight into the potential relevance of how relational representations/ schemas, interpersonal cognition, and adult attachment can influence lay referral, and professional healthcare help-seeking behaviour. These findings are supported by previous literature which provides evidence of how adult attachment style and intergenerational family support may influence the receipt of familial support and suggestions in the attachment literature with regards to potential

future lines of inquiry (Merz & Consedine, 2009; Mikulincer & Shaver, 2020). Moreover, the findings exemplify the role of the familial environment and how this may shape how people learn (cognitive-affect schemas) to form close relationships and how to provide and receive relational support during times of threat or challenge. In consequence of the above and building upon the findings of our IPA study (Chapter four), this mixed and multi-methods study (Chapter five) aimed to explore people's illness perceptions of bodily changes, lay referral, and help-seeking behaviour in the context of (seeking) healthcare professional advice during the COVID-19 pandemic. In order to build upon previous theory informed research and the IPA study findings; the theoretical orientation of this study will be the Common-Sense Model of Self-Regulation (CSM) (Leventhal et al., 1992), Adult Attachment Theory (Brennan et al., 1998), and Bartholomew's (1990) four-category model of self and others. Lay referral and help-seeking behaviour will be considered in relation to attachment theory at an individual level (an exploration of individual people or small groups). This will enable the exploration of lay referral in terms of people's interpersonal development, social interaction, and patterns of adult attachment during the COVID-19 pandemic when they experience bodily changes which may or may not be cancerous illness symptoms (Duschinsky, 2020; Fraley & Shaver, 2008).

Aims and Objectives

The objective of this study is to examine and build on existing evidence of the influence of illness perceptions, personal factors, and adult attachment style on people's thoughts, emotions, and coping responses; whilst also exploring how adult attachment style influences people's narratives in relation to lay referral and consultation behaviour in the context of the experience of bodily changes during a world pandemic. This study will draw upon a range of methods, methods of data collection, and analytical strategies to enable a pluralistic approach to the exploration of the topic (as discussed below). The use of different methods is considered to be an advantage and was inspired by the attachment literature which uses interviews and/ or self-report measures. Here, different elements and concepts associated with these approaches will be adapted for the purpose of this study. The below outlines the research questions, each holding equal value in terms of the data produced through multiple methods, and results generated through differing analytical strategies.

In terms of the quantitative analysis, it is hypothesized that:

Personal factors (gender, life stage, attachment), situational stimuli i.e., symptoms/bodily changes, and previous illness experience will influence people's illness perceptions, lay referral, and help-seeking behaviour during the pandemic

In regard to the theoretically driven abductive qualitative template analysis, the research question is:

How does adult attachment influence lay referral and help-seeking behaviour in the context of professional healthcare advice during a world pandemic?

Methods Section

A Pluralist Approach

This study took a pluralist approach, which refers to the use of different quantitative or qualitative methods across paradigms or the integration of quantitative or qualitative methods within a paradigm (Chamberlain et al., 2011; Frost et al., 2011; Shaw, 2019). The study aimed to include different methods of data collection and different analytical processes. This was considered an advantage that could add depth to the study and the knowledge produced through the use of multiple methods and the interpretations generated through several conceptual lenses (Shaw & Frost, 2015). This approach created diversity and provided an important opportunity to examine the interconnected nature of the social world and people's relationships. Pluralism also enabled the exploration of the relationships between different methods, how they connected, and how they 'meshed'. The process of 'meshing' different methods required the researcher to engage with dialectical thinking, the holding of several different ideas together, whilst considering their relationship with one another and how these ideas complemented, created tension, or contradicted each other (Marks, 2006). This approach, therefore, aimed to potentially overcome the critique of previous research.

Overall Ontology and Epistemological Stance

The ontological assumptions and overall epistemological stance of this Chapter although includes several different approaches, methods, and paradigms are underpinned by a realism ontology (there is a ‘singular truth’ ‘out there’ that the researcher is able to access through research) and a positivist epistemological framework. This is in alignment with more traditional mainstream quantitative approaches in psychology (King, 2012). The rationale for this overall stance in connection to the various methods used is discussed further later in this Chapter as part of the methods section and the researcher’s reflexive notes.

The Overall Study Design (Part One and Two)

This study adopts a novel integrated concurrent triangulated pluralistic mixed and multi-methods comparison design (see figure 5.3) (Creswell, 2013; Frost, 2011; Rugg, 2010). This means that both parts of the study run at the same time, and that the pluralist approach facilitates the use of different methods across and within paradigms. The methods and data collection in the study design differ, although the advantage of pluralism is that it can add depth to the knowledge produced through multiple ontological characteristics and the interpretations developed through several lenses (Frost, 2011). A triangulation of the results gathered through each of the stages as part of the study design also offers an opportunity to converge the differing data produced and the different types of results generated through each of the approaches. Given the outlined theoretical orientation of this study, a multi-dimensional and ontological pluralist approach that incorporated a quantitative and a qualitative abductive reasoning component was considered appropriate. This was considered best suited to address the complexity of the theoretically-driven research question and the goal of extending our understanding through the use of differing methods. Here, each of the analytical strategies were chosen and planned prior to data collection to build upon the previous literature (as discussed in more detail below). This included an abductive approach as part of the qualitative component which placed value upon a reciprocal dialogue between pre-existing attachment related psychological theory (deductive) and the participants’ data (inductive) to develop and build upon existing theory (see figure 5.1 and 5.2). As part of this study design, both the quantitative and qualitative components hold equal value, with

neither taking priority, and each considered important in reference to the different types of topical knowledge produced.

Figure 5.1

Methods Triangulation

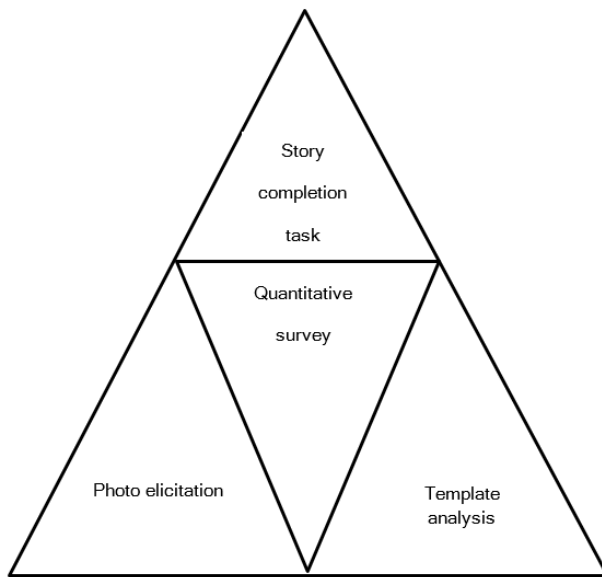
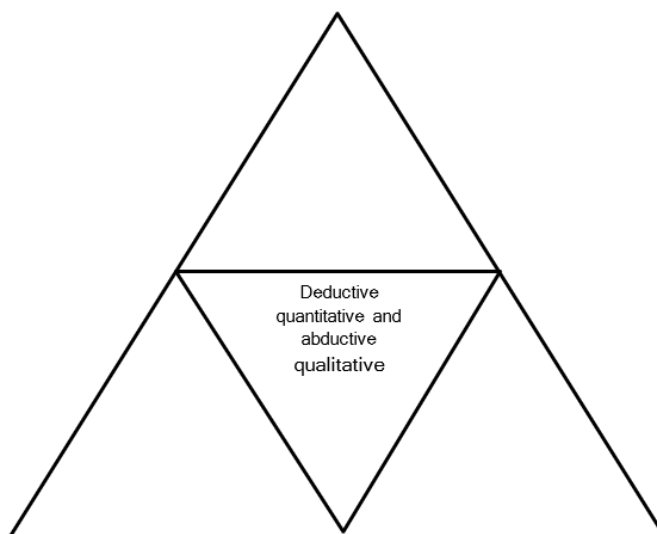


Figure 5.2

Analysis Triangulation

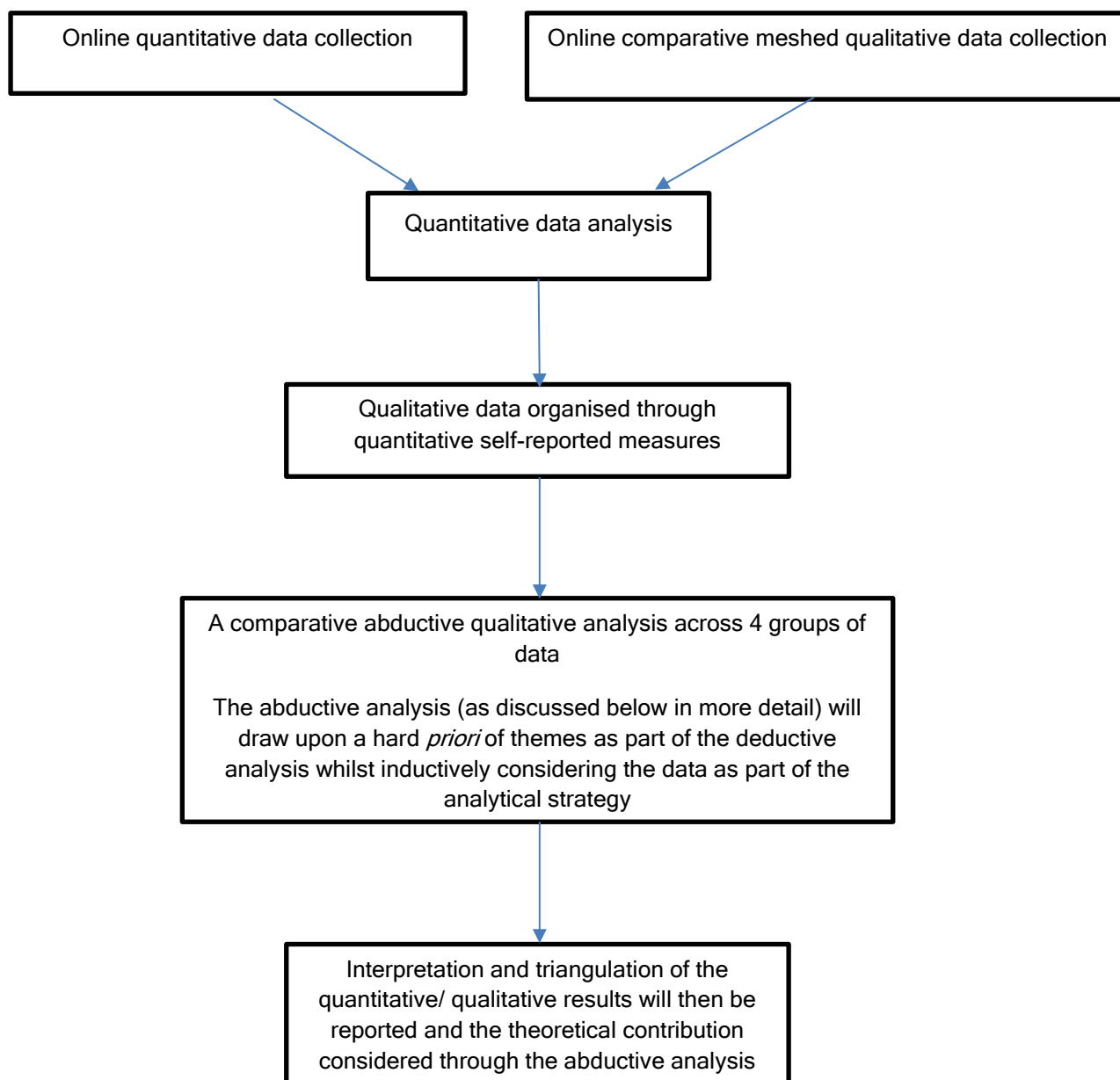


Overall Method of Data Collection

The study was presented as an online survey on Bristol Online Surveys (BOS).

Figure 5.3

Overall Study Design



Online Data Collection Methods

A Retrospective Cross-sectional Quantitative Design

A retrospective (with the experience of bodily changes that may or may not be cancerous symptoms occurring within the previous three months) cross-sectional design was employed (with data collected and captured at a singular time point).

Standardised Measures. The following measures were used:

1. The Experiences in Close Relationship scale (ECR) (Brennan et al., 1998) (appendix I) was used to assess attachment. The ECR has 36 items, each scored on a 7 point, partly anchored, Likert-type scale ranging from 1 (disagree strongly) to 7 (agree strongly). Brennan (1998) reported high reliability of this scale (a Cronbach's alpha of 0.91 and 0.94 for anxiety and avoidance respectively) and in the current study this was also shown ($\alpha = 0.917$). The ECR scale (1998) was electronically sourced from Professor Kelly Brennan-Jones at the State University of New York. The ECR was selected (as opposed to the short version) as the self-reported scores could be interpreted with reference to the different adult attachment styles as opposed to 'secure' versus 'insecure' attachment orientations alone and this better fitted the current study objectives.
2. The Brief Illness Perception Questionnaire (BIPQ) (Broadbent et al., 2006) (appendix J) was used to assess illness representations. The Brief Illness Perception Questionnaire contains 8 single items, each scored on a continuous linear scale (0-10) and one rank order question about causation. Broadbent et al. (2015) conducted a systematic review and meta-analysis with regards to the BIPQ. Results concluded that the BIPQ has good psychometric properties in terms of good concurrent validity, and predictive validity. The BIPQ was selected as opposed to the original IPQ/ IPQ-R, as it provides a more rapid assessment of illness perception (i.e., 9 items opposed to 50 items as part of the IPQ) which was considered important given the design of this study and to reduce how long the online survey would take. Permission was sought from Professor Elizabeth Broadbent at the University of Auckland.

3. A purpose-built questionnaire with demographics and items addressing lay referral was developed for the current study and will be referred to as the Lay Referral Measure (LRM) (Campbell, Morrison & Huws, 2020) (appendix K). The LRM includes 16 items (e.g., demographics/ did you speak with anyone about your bodily changes or illness symptoms? If so, how many people? Please could you indicate the duration of your relationship with the person you mainly speak with about your bodily changes or illness symptoms? Was there a particular reason you mainly spoke to this person?) and was constructed based upon the previous socially oriented literature. The LRM combines nominal/ ordinal variables which were single items, scored in a unitary manner, subject to an expert review and a multi stage pilot process as part of the overall design. The LRM survey was subject to the survey development process as outlined in Chapter two.

Sample Size Estimation

A priori statistical power analysis was calculated to gain sample size estimation for F tests in regards to the main overall hypothesis of the quantitative study. As this was, to the researcher's knowledge, the first study to explore the how adult attachment influences lay referral, the calculation has not been based on a previous study. A medium effect size (ES) of 0.15 (in terms of ES in regression) formed part of the calculation to give a meaningful effect in accordance with Cohen's (1988) criteria. The alpha was set at = .05 and power = 0.80, and the projected sample size needed with this effect size (GPower 3.1) is approximately N= 85.

Online Qualitative Data Collection Methods

A Comparative Retrospective Pluralistic Meshed Qualitative Cross-sectional Design

The below outlines the key design characteristics of the study:

- The study design was chosen to address the theoretical nature of the research
- A comparative study design was included to enable the comparison of four different qualitative sets of data

- The study was retrospective in nature with those who took part experiencing bodily changes that may or may not be cancerous illness symptoms occurring within the previous three months, and
- A cross-sectional design was employed, with data collected and captured at a singular time point.

The story completion method (SC) (Clarke et al., 2019) was selected as part of the qualitative component as unlike other qualitative methods, SC lends itself well to a comparative design (Braun & Clarke, 2013) and has been exemplified in psychological qualitative research through the work of Jennings et al. (2018). Story completion (SC) is a relatively new method of narrative inquiry in psychology and has the potential to create contextual insight (Clarke et al., 2019). It is a creative qualitative method of data collection that offers an alternative to qualitative approaches such as face-to-face interviews, focus groups, and self-report diaries. Rather, SC invites participants to write a story in response to a hypothetical scenario pre-determined by the researcher. SC method can therefore enable people to externalise their perceptions, feelings, behaviours, and motivations, and stories can be understood as reflecting the discourses that participants use in making sense of their experience (Kitzinger & Powell, 1995).

SC scenarios are presented in the form of story 'stems' or 'cues' with an instruction guide detailing how participants need to complete the task. Basic 'stem' designs are developed by the researcher, but they require considered formulation as each word used as part of the 'stem' or 'cue' needs to be carefully constructed to optimise how meaning is elicited from participants. They are neutrally written so that they do not represent any particular social group or categories, and they are purposely ambiguous so that participants can attach their own meaning and interpretation to the presented scenarios (Clarke et al., 2019). Story 'stems' or 'cues' can be developed in a first or third person position. Unlike the more direct first-person position, third person story stems prompt participants to write about a hypothetical scenario and fictional character (Hunt et al., 2018). These have been found to reduce socially desirable responses that are often elicited through face-to-face narratives, and are therefore useful when exploring emotive, difficult, or challenging topics (Clarke et al., 2019). SC data also lends itself well to comparative research designs in which different group responses (e.g. grouped by gender) can

be compared in terms of their responses to the same 'stems' or 'cues' (Kitzinger & Powell, 1995). Therefore, an online first person 'story stem' and written text cue was presented to the participants. The 'story stem' took a first-person position in order to gain narrative text data in reference to how and/ or if the COVID-19 pandemic has influenced lay referral and help-seeking behaviour. It was an important aspect of this study to acknowledge the COVID-19 pandemic and how this contextual factor may also shape the participants' responses to bodily changes during this period. The story 'stem' was formulated purposely short in length although presented enough information to openly guide the participants to the topical focus of the study and was sufficiently ambiguous to hypothetically set the scene in terms of lay referral and help-seeking. The aim was that the story stem was non-directional in that it did not impose nor insinuate engagement or not with lay referral/ help-seeking and aimed to encourage participants to make sense of the 'story stem' (Clarke et al., 2019).

A Novel Integration of Photo Elicitation within the Story Completion Method

This study integrated a strand of photo elicitation (PE) within the 'story stem' to create an accompanying online visual cue (see figure 5.4). The use of photo-elicitation was part of the researcher's attempt to not impose categories of illness, illness symptoms, or health related experiences upon the participants; but to elicit the participants' reflective thoughts, feelings, and perceptions in relation to lay referral and help-seeking behaviour in the context of the COVID-19 pandemic (Bates et al., 2017). PE is a creative method in which either a single photo or series of photographs are used as part of the data collection process. Photographs are used as visual stimuli to elicit participant responses, thoughts, views, beliefs, ideas, and feelings (Glaw et al., 2017). PE is generally used with face-to-face interviews to elicit the narrative expression of emotion and is widely used to help people to expand their understanding of their own and others' social realities (Bates et al., 2017). For example, Linz (2011) applied PE as an educational strategy as part of the teaching process to elicit learners' emotions and a dialogue relating to stereotypes and stigma in healthcare. Therefore, the integration of PE with SC offered an additional layer to the data collection and was considered as having potential to enhance likelihood of obtaining meaningful participant data. As far as it is known the integration of PE with the SC method has not conducted before. When considering which images could be used as part of the study, the copyright library group at Bangor University were

consulted, the below image can be used for non-commercial use or within the organization only.

Figure 5.4

COVID-19 Visual Cue

**Image removed due to copyright*

‘Meshing’ and the Study Design

The ‘meshing’ of the SC method and photo elicitation reflects the advantages of a pluralist approach (as outlined in the overall study design section). In this study the two methods are combined in an innovative way which has not been conducted before, to explore how adult attachment style influences lay referral and consultation behaviour when people experience bodily changes in a world pandemic.

Reflexivity; The Study Design Process

Reflexivity as part of the study design was achieved through developing a reflexive synthesis when considering the methods and how to resolve conflicting elements of the approaches (Marks, 2006). The below in turn presents a series of first-person ‘working progress’ reflexive notes (as part of a second-level of reflexivity) in note format to provide insight to the research design process. This offers the reader an insight and a commentary across the process (Frost, 2011). For more information about the role of reflexivity as part of this study see Chapter two in reference to quality criteria.

NOTE 1: Reflexivity is important as the initial study design process often felt like spinning intellectual plates of knowledge in terms of ontological assumptions, epistemologies, how to capture context, and learning how the methods align, co-exist, complement, or create tension and incongruities. The approach to the study design has been through a sensitive dialectical manner; this was to prevent feeling/ becoming dizzy and as to not to smash the plates beyond repair when the task became challenging. There is a sense of excitement but also a tone of uncertainty about the unknown when thinking about proposing how to 'mesh' the methods as part of this study. Another important point for reflection has been the emergence of the 2020 coronavirus pandemic in terms of researching the research topic of symptom perceptions and responses and also its implications for the context in which the study will be conducted. For safety, it has been decided that data collection will take place online rather than face-to-face as initially planned.

NOTE 2: The below notes refer to the complementary aspects of SC in terms of the topic. It was when the topic of bodily changes and potentially cancerous illness symptoms appeared to align with the story completion method that the spinning of plates in relation to the different components of the study design started to move more synchronously.

| Previous Research Topics | Complementary Topical Aspects |
|--|---|
| <p><i>Feminist psychology has successfully used story completion as a research tool to gather data about a range of potentially challenging and emotive topics (i.e.-sexual experimentation, sexuality, eating disorders).</i></p> | <p><i>The broad focus of this current study is to explore bodily changes/ illness symptoms which appeared to align with the wider literature in reference to the potentially emotional nature of the topic.</i></p> |
| <p><i>Story completion has been previously employed in the developmental literature with regards to dyadic relational representation and attachment theory.</i></p> | <p><i>This provided evidence that story completion could facilitate a method of narrative inquiry in the context of attachment theory.</i></p> |

NOTE 3: The below notes refer to the complementary 'meshing' aspects of SC and photo elicitation. Each of methods appear to complement each other and are thought to bring value to the study design.

| <i>Previous Research Topics</i> | <i>Complementary Aspects of SC with Photo Elicitation</i> |
|---|--|
| <i>Previous research has employed photo elicitation to prompt health-related narrative or discussions about relationships and different emotive topics.</i> | <i>Both photo elicitation and SC explore the potentially emotive and challenging topics of symptom perception and response. Each offer a unique and creative form of data collection which may inductively enhance our understanding in health psychology.</i> |
| <i>Previous research has used PE to elicit discussions about people's thoughts, feelings, attitudes and beliefs.</i> | <i>The use of visual stimuli in projective methods has been discussed above and refers to perceptual and cognitive processes. Visual stimuli could also be pre-determined to elicit health related narratives in conjunction with a pre-determined story 'stem'.</i> |

| NOTE 4: Previous Research from a Methods Perspective | Complementary Aspects from a Methods Perspective |
|---|--|
| <i>Story completion can be conducted from an essentialist position (the assumption that psychological meaning such as attitudes, thoughts, and feelings can be elicited through the data (Kitzinger & Powell, 1995) to enable the exploration of people's thoughts, feelings, and motivation.</i> | <i>An essentialist approach that focuses upon what lies behind the stories opposed to just story content will help us to understand how adult attachment and relational representations influence lay referral and help-seeking behaviour.</i> |
| <i>Story completion can present first person and /or third person hypothetical story 'stems' or 'cues'.</i> | <i>First person story 'stems' will facilitate the exploration of a range of bodily changes including potentially cancerous illness symptoms (even with a sample of people who do not or have not experienced cancer).</i> |
| <i>Previous research has suggested that story completion data can make reference to and enable the expression of non-socially desirable responses.</i> | <i>Data generated through story completion may contribute to our understanding of lay referral and help-seeking behaviour beyond socially desirable responses (i.e., that people automatically and/ or rationally seek healthcare advice).</i> |
| <i>In accordance with previous research designs, story completion can be used as a comparative design to examine group differences (i.e., gender differences) (Kitzinger & Powell, 1995).</i> | <i>The comparable aspect of story completion is useful and will enable the comparison of data across different adult attachment styles (secure, preoccupied, dismissing and, fearful-avoidant).</i> |
| <i>There is evidence to suggest that projective techniques and the use of visual stimuli can provide insight into individual cognitive and perceptual processes.</i> | <i>The use of projective techniques in the literature leads to the below discussion about photo elicitation and the use of visual stimuli.</i> |

NOTE 5: *When considering the comparative SC design and the influence of the pandemic upon people's social context, relationships, and restricted socialization; the researcher intends to acknowledge the potential impact of the pandemic upon people's self-reported scores (the quality of their close relationships). For instance, the sample size for each adult attachment style will be reported, considered in terms of the refinement of the organisation of data, analysis, and write-up post data collection. This iterative process is in alignment with the SC method as pervious noted by Clarke et al (2019) who highlighted the unpredictable 'wait and see' nature of this type of research.*

The unpredictability of the context in which this study will take place (due to the Coronavirus pandemic) created a sense of tension. However, after much deliberation, it is accepted that SC is a relatively new method in qualitative psychology and in itself brings about uncertainty.

What originally appeared to disrupt the synchronized spinning of plates and 'meshed' methods became an integral part of the learning process when design the proposed study design. An attitude of acceptance has been developed for the unknown and an appreciation for each of the methods in their own right.

Reflexive Visual Art-Based Metaphors; A Process of Creative Consolidation During the Study Design Process

Given the challenges of pluralistic research designs, as well as developing a reflexive narrative, a series of creative visual art-based metaphors have been designed and mapped. These have been created by the researcher herself. Art-based methods have been used in the literature in connection to reflexivity in other fields such as education, teaching, and learning (i.e., Bogumil et al., 2015), with art-based reflexivity offering an opportunity to consider people's values, ethical issues, and the methodological processes to research. However, the creation of specific visual metaphors was the focus to express and map the study design process. As far as the researcher is aware, the use of visual metaphors created to express and map

the process is a unique approach developed as part of this thesis. The integration of these art-based images aimed to tell a story, expressing the situational context (i.e., the COVID-19 pandemic) of the study, emotions, and challenges that the researcher faced. Metaphors have been defined in the literature by Lakoff and Johenson (1980) as cited in Stone and Everts (2006) as:

‘... the essence of metaphor is understanding and experiencing one thing in terms of another...’

The above definition resonated with the researcher and provided a space to visually map (see the below figure 5.5) three specific points of the study design. It was therefore, the process of engaging within the activity as opposed to the product or outcome of the image which was of importance.

Figure 5.5

A Three Point Visual Metaphor Map of The Mixed and Multi-methods Study Design Process

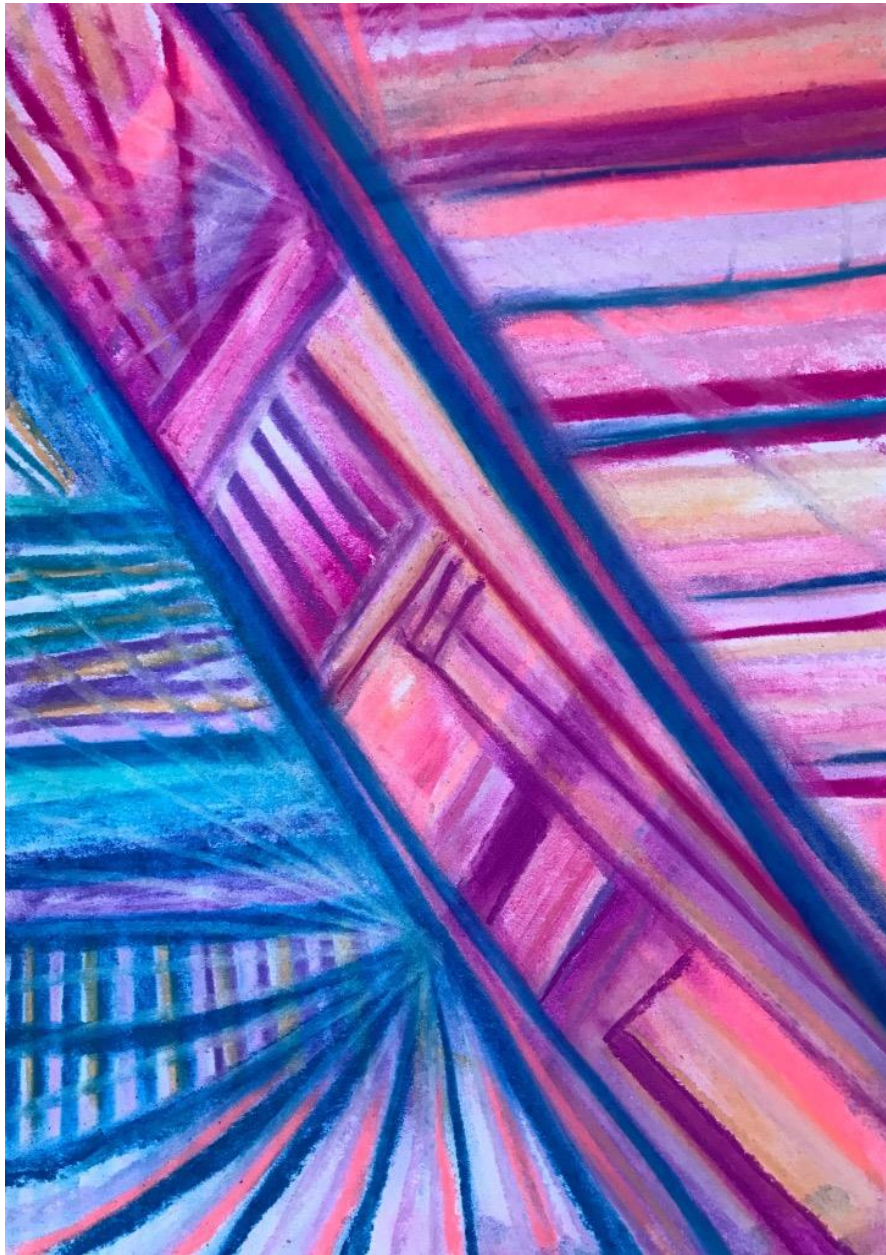
Point one

Taking context into account, this image was created by the researcher to express how she experienced waves of new learning simultaneously to the waves and peaks of the COVID-19 pandemic. The magnitude of the task and adaption during this time was important to facilitate the continuation of the study.

'Peaks and Waves of Learning During The COVID-19 Pandemic'

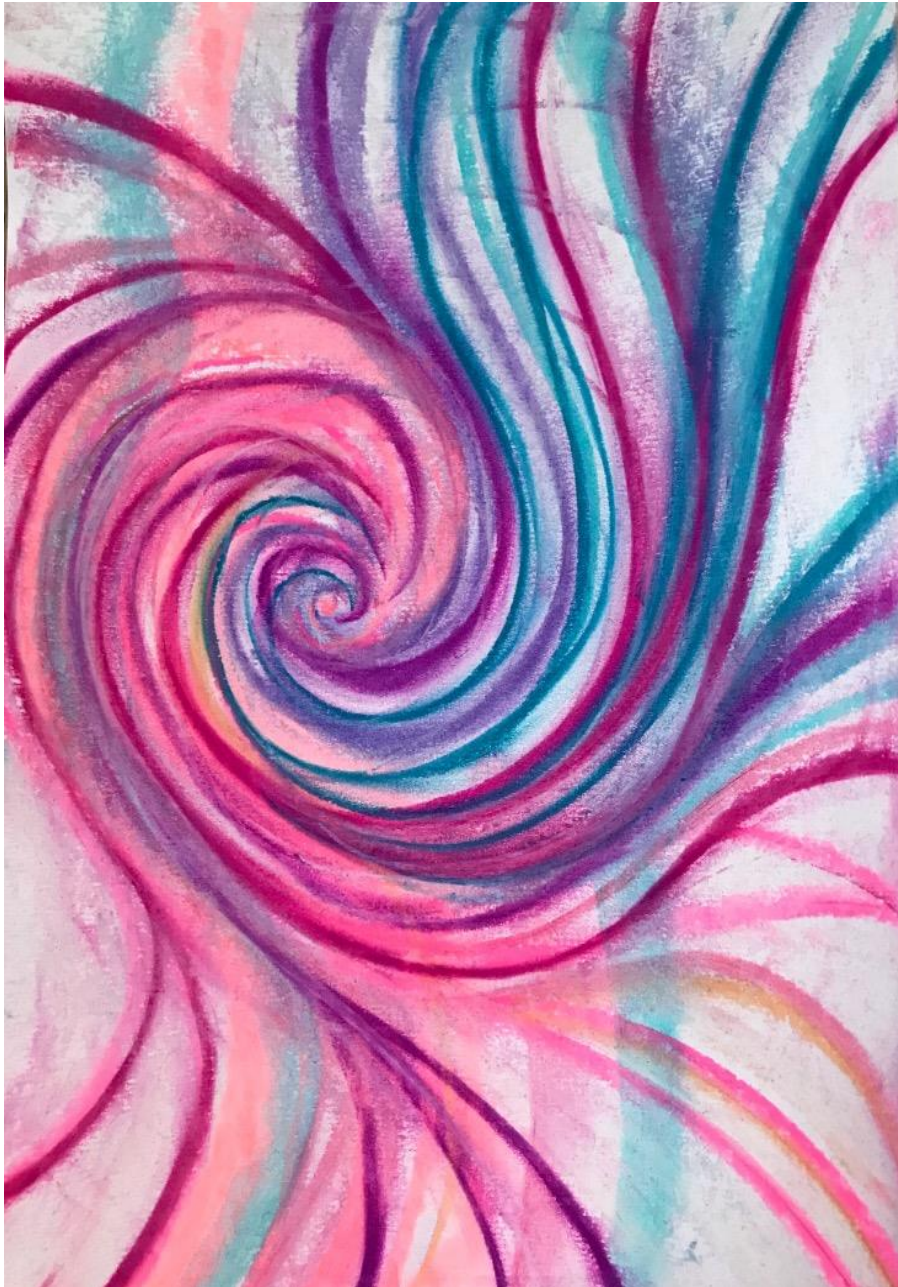
Point Two

This image expresses a sense of holding multiple paradigms and ontologies in mind during pluralistic research. Each of the methods used in Chapter five brought differing although at times complementary perspectives. This is expressed through the use of colour and the differing angles of the lines which meet in the centre of the page.

‘Multiple Sources’

Point three

The below represents the 'meshing' integration and consolidation of bringing together different paradigms, methods and knowledge.

'Brining it Together'

Participant Recruitment; an Online Website, Social Media Method and Organisations as Gatekeepers

The study was promoted online and through social media (Twitter and Facebook, but not exclusive to) in collaboration with Tenovus Cancer Care, KESS2, Bangor University (Bangor University social media, organisational email, the Doctoral School), Breast Cancer Now and Wales Cancer Alliance. Tenovus Cancer Care supported participant recruitment as part of a partnership with the Knowledge Economy Skills Partnership 2 (KESS2) programme and we drew upon Tenovus Research Team, Tenovus social media, and Friends of Tenovus. Other charitable organisations were contacted although either declined or no response was provided (i.e., Marie Curie, Macmillan, St John's Ambulance, Bowel Cancer UK). No statutory agents, National Health Service (NHS) boards, or NHS trusts were approached. Organisational email, intranet, and internal mailing lists were also used to increase the reach of recruitment promotion (e.g., across psychology, health sciences, education, medical sciences and sports, health and exercise sciences at Bangor University). Bangor University Student Participant Panel (SONA) was selected as a recruitment method. For the online study advertisement used on social media etc. (see appendix L). The overall sample (N=94) and the method of recruitment for each participant is not reported as the online survey (BOS) was an external link provided through the above methods.

Participants

Eligibility, inclusion and exclusion criteria are outlined below in table 5.1.

Table 5.1

Participant Eligibility

| Participant Eligibility | Criteria |
|-------------------------|--|
| Inclusion | Have experienced self-reported bodily changes or physical illness symptoms in the last 3 months Be over 18 years of age |

| | |
|-----------|--|
| | Have the capacity and willingness to provide informed consent |
| | Have a self-declared cognitive and physical capacity to complete the questionnaire online |
| Exclusion | Have not experienced any bodily changes or physical illness symptoms in the last three months |
| | Lack the capacity to provide consent |
| | Have insufficient cognitive or communicative abilities to enable participation (self-declared) |
| | Are under the age of 18 years old |

Procedure

Ethical approval was granted for this study (2020-16774) by the Healthcare and Medical Sciences Academic Ethics Committee Bangor University. The application adhered to the British Psychological Society's Code of Human Research Ethics (2014). Part one and two of the online study was uploaded to Bristol Online Surveys (BOS) as supported by Bangor University. This included a participant information sheet (appendix M) (available in both an English and Welsh version), an online informed consent form (appendix N), measures, visual stimuli and narrative cues (see the below). As part of the online study design, and consent process the participants were presented with an online consent form. Here the participants could read, consider, consent (agree) or not consent (disagree) to take part in the online study. For those who consented to take part in the study, an option was available to print or save a PDF of the survey which included the online consent form. Those who did not consent to take part in the study or did not self-report to fit the eligibility criteria were directed away from the study through a screening functionality as part of BOS. The participants' wish to withdraw at any stage of the project was respected.

Ethical Considerations

Anonymity and Confidentiality

The project gathered personal information and therefore aimed for anonymity and confidentiality. Data collected was safely stored/ kept securely upon an

encrypted one-drive (Microsoft Teams) and/ or u-drive device in accordance with the Bangor University research data management policy. Data will not be disclosed to any unauthorized parties. Personal identifiable numbers were used as part of the analysis process, and write-up (i.e., *P9-FA-SC1*) which outlined the participant number (from 1-94) and their self-reported adult attachment style group (FA= fearful-avoidant). Possible pseudonyms may also be considered in terms of data presented at conferences and/ or within potential publications although as part of this Chapter personal identifiable numbers were used given the large sample size (N=94).

Psychological Harm

Potential distress was not anticipated by the team. However, to reduce any possible psychological harm such as participant distress, participants were able to omit survey questions and able to withdraw from the study at any point. As part of the participant information sheet, it was suggested if the online study should create any later questions that the participants could contact a member of their healthcare team, or local helplines for support.

The Overall Development of the Online Study

Online Quantitative Survey Development

The online survey was developed in relation to the projects research question with a battery of standardised measures, demographic questions and the LRM being derived from empirical literature. The quantity of measures employed in this study was carefully considered in order to prevent participant fatigue. All previously validated measures were sourced and transferred onto BOS.

Online Story Completion Development

The length of the 'story stem' was brief, facilitated a sense of ambiguity although presented enough information to openly guide the participants to interpret the scenario (Clarke et al., 2019). The 'story stem' was presented alongside a pre-determined image (visual stimuli) and purposely selected to minimise any gendered characteristics. The image did not present hair or recognisable body parts and was chosen to elicit the participant's thoughts, feelings, and attitudes (see below).

Story Completion Participant Instructions. Participants were presented with the following completion instructions based upon Clarke et al. (2017) who developed a practical guide to data collection with regards to textual, and media techniques. As part of the guide there was a particular focus upon the use of the Story Completion method. This encompassed the use of the Story Completion method with first person ‘story stems’ to gather data from the participants’ own standpoint (see figure 5.6 for the story stem).

“You are invited to complete this story- this means that you read the opening sentences of each story and then write what happens next. There is no right or wrong way to complete the story, and you can be as creative as you like. The online study is interested in the range of different stories that people can tell us. Don’t spend too long thinking about what might happen next – just write about whatever first comes to mind. Because collecting detailed stories is important, you are invited to write a story over 200 words long. Some details of the opening sentence of the three stories are deliberately vague; it’s up to you to be creative and ‘fill in the blanks.’”

Figure 5.6

Photo Elicitation (COVID-19 Visual Cue) and the ‘Story Stem’ Question

****Image removed due to copyright***

“Many people have recently been experiencing different illness symptoms and bodily changes which may or may not be related to the COVID-19 outbreak. Has the outbreak of COVID-19 changed whom you spoke to about your bodily changes and illness symptoms and why? For example, could you explain if you (or if you did not) speak with any of your family, friends or gained healthcare professional advice?”

Pilot Study

An online pilot was conducted to assess the usability of BOS, the survey questions, the participant instructions, online platform usability for the participants and how the researcher could transfer data to SPSS. The hyperlink for the online survey was checked in advance to ensure people could gain access. In total, the multi stage pilot took four stages which are each described in table 5.2 below, includes the number of participants that took part in each stage.

Table 5.2

Stages of the Pilot

| Stages of Pilot | Action and Adaption |
|-----------------|---|
| One | <p>Action</p> <p>Online survey, sent to expert supervisory team (N=2) and to pilot participants (N=4)</p> <p>Adaptions</p> <ul style="list-style-type: none"> • Advanced option used in BOS in terms of participants' details and consent procedures, consent required to progress and if no consent provided, participants re-directed out of the study • Integrated an edibility section • Included a text statement between the quantitative and qualitative data collection stages • Included a text statement at the end of the study which showed the online survey had finished • SC text boxes made bigger • Separated the measures over more than one page |
| Two | <p>Action</p> <p>Re-developed aspects of the online survey and re-piloted qualitative with pilot participants (N=3). Adjust post further feedback</p> |

| Stages of Pilot | Action and Adaption |
|-----------------|--|
| | Adaption <ul style="list-style-type: none"> • Re-formulated the story completion section based upon feedback and re-piloted |
| Three | Action <p>The adjusted online survey was sent to expert supervisory team (N=2)</p> |
| Four | Action <p>Project discussion and team agreed the launch of the online study</p> |

Project Management and Data Collection of the Actual Study

The researcher tracked recruitment and regularly reported the on-going sample size to the supervisory team. Data collected was safely stored/ kept securely upon an encrypted one-drive (Microsoft Teams) and/ or a u-drive device in accordance with the Bangor University research data management policy. Data has not been disclosed to any unauthorized parties and will also be disposed of under Bangor University Policies (minimum institutional retention period for research data is 5 years). The project ran until the required sample size was achieved and in terms of the end date of the study (N=95 took part).

Quantitative Data Analysis

Statistical Analysis

The cross-sectional statistical analysis involved: data being examined for normality, identification of outliers and missing data in SPSS; determination of group descriptive and inferential statistics (non-parametric when required due to non-

normality, violation of assumptions with regards to normality) to describe the sample and examine subgroups within it (chi-squares, etc.) and the regression modelling to explain variance in lay referral behaviour. Mediation analysis to test whether any of the variables (i.e., illness perceptions, lay referral, attachment style, help-seeking) influenced the extent of the effect in connection to the outcome was considered but assumptions were not met and so this was not conducted.

Qualitative Story Completion Data Analysis

Organisation of the Comparative Data

The qualitative SC data was organised into four adult attachment style groups (secure, preoccupied, dismissing, and fearful-avoidant) informed through the participants' self-reported scores from The Experiences in Close Relationship scale (ECR) (Brennan et al., 1998). Data was transferred from Bristol Online Survey to SPSS and the individual adult attachment style of every participant was calculated and recorded. The overall initial sample was N=94, with two data sets subsequently excluded based upon the participants' response (with one of the SC data sets also excluded because the same participant omitted 16.66% (over 10% missing; Peng, 2006) ECR scale questions) in terms of missing data. In order to calculate adult attachment style for the SC data organisation, 8 of the remaining 92 participants omitted 1 question, and 1 participant omitted 2 questions. In these cases, a person mean substitution was calculated and these participants' data were included. A total of N=92 SC data sets were therefore included in the organisation. Each of the participants' SC qualitative data was then labelled in terms of adult attachment style and an anonymous person identification number. The SC data was then reorganised into four separate adult attachment style groups which created the 4 sets of comparable data (see table 5.3).

Table 5.3

Comparative Data Organisation

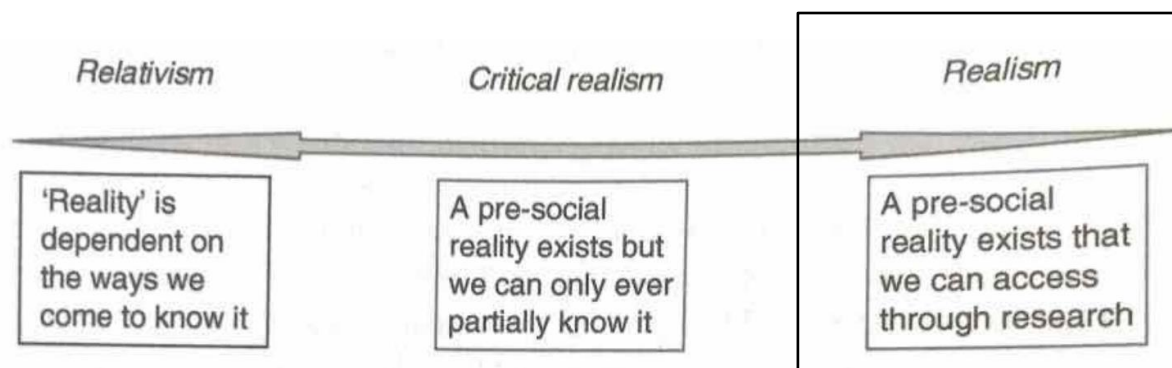
| Adult Attachment Style | Covid-19 Stimuli |
|------------------------|------------------|
|------------------------|------------------|

| | |
|-----------------------------------|---------------------------|
| Secure attachment style | Secure Covid-19 |
| Preoccupied attachment style | Preoccupied Covid-19 |
| Dismissing attachment style | Dismissing Covid-19 |
| Fearful-avoidant attachment style | Fearful-avoidant Covid-19 |

Qualitative Analysis

Template Analysis, Ontology and the Epistemological Stance

Template analysis is a pragmatic form of thematic analysis based on hierarchical coding and provides a high level of structure when analysing data whilst also facilitating an iterative process of adaption (Brooks et al., 2015). Template analysis, as with thematic analysis can be considered through multiple different theoretical positions and epistemological lenses which is different from approaches such as grounded theory which have a particular theoretical foundation (Brooks et al., 2015). The epistemological flexibility that template analysis provides, means that it is a valuable approach that can be applied to many different topics, research questions and can be adopted from several positions such as a realist or a constructivist position (King & Brooks, 2017). Template analysis was chosen as part of this study and underpinned by a realism ontology (there is a 'singular truth' 'out there' that the researcher is able to access through research) (see figure 5.7) and a positivist epistemological framework.

Figure 5.7*The Ontology Continuum*

Source: Braun, V., & Clarke, V. (2013). *Successful qualitative research*. SAGE Publications Ltd.

One of the main components of template analysis is the formulation of a coding template (King & Brooks, 2017). The development of *a priori* themes before data analysis is typical when using template analysis although not essential. *A priori* themes are generally created on the deductive assumption that the research topic and research question will be examined in terms of the existing literature. This approach is particularly useful in terms of building upon previous research and theory. Throughout the analytical process, template analysis is non-prescriptive, provides flexibility, does not define itself concerning descriptive or interpretative analysis, and differs from traditional thematic analysis (Brooks et al., 2015). Theme development is an iterative process of abductive development and reformulation. Themes may also be removed during the analysis process if they are perceived as no longer helpful to the research question. Here, the iterative process offers a form of triangulation to ensure that all stages of the analytical strategy relate to the research question.

This iterative process can be exemplified by the work of Kirkby-Geddes et al. (2012). These authors used the theoretical concepts of 'bridging' and 'bonding' from a social capital perspective to develop strong *a priori* themes when exploring people's experiences of engaging within community groups. Overall, the study reported that the theoretically informed *a priori* themes were a useful starting point that helped to develop the two concepts in relation to the project which captured the complexity of the topic. Therefore, template analysis in the context of narrative data

gathered through the story completion method was considered to be a novel approach; with template analysis providing a flexible approach that included a deductive, inductive and abductive method of analysis to build upon existing theory.

NOTE 6: In terms of 'meshing', template analysis aligns, and complements story completion which added value to the study design. This was generally based upon the flexibility of template analysis which offered a method rather than a methodology underpinned by a particular set of philosophical assumptions.

Other methods of analysis have been considered; this includes those which have been previously used in the SC literature (i.e., content analysis). The rationale for not using content analysis as part of the current study design was that although the method could be deductively or inductively used in reference to textual data and focus upon social interaction; it does not involve an abductive dialogue between the themes and data to develop existing theory which we sought for in the current study.

A Priori of Themes

The *a priori* themes (developed in advance of coding) were formulated based upon Bartholomew's (1990) theoretical four-category diagram of the model of self and others (figure 5.8) (see appendix O). The assumption was that aspects of attachment theory such as a concept of self and concept of other influence the lay referral and help-seeking behaviour. The *a priori* of themes were classed as a hard *a priori* themes in connection with King et al. (2018). The hard nature of the *a priori* themes was based upon the project taking a theoretical orientation in which the *a priori* themes are well developed and defined in the context of attachment theory. In this case Bartholomew's (1990) theoretical four-category diagram of the model of self and others (see the below table 5.4 for the *a priori* of themes) was drawn upon. Here, the rationale of developing a priori of themes was situated in the goal of examining the participant's narrative data through a theoretically pre-defined attachment lens. This approach was developed and inspired through the attachment literature that not only uses self-reported measures but also interview data.

Figure 5.8*A Model of Self and Other*

| | | MODEL OF SELF (Dependence) | |
|---------------------------------------|----------------------------|--|---|
| | | Positive (Low) | Negative (High) |
| MODEL OF OTHER (Avoidance) | Positive (Low) | CELL I SECURE Comfortable with intimacy and autonomy | CELL II PREOCCUPIED Preoccupied with relationships |
| | Negative (High) | CELL IV DISMISSING Dismissing of intimacy Counter-dependent | CELL III FEARFUL Fearful of intimacy Socially avoidant |

Source: Bartholomew (1990) <https://doi.org/10.1177%2F0265407590072001>

Table 5.4*A Priori of Themes*

| Adult Attachment Style (placeholder codes) | <i>A Priori</i> Themes Based Upon a Concept of Self and Other |
|---|--|
| Secure template | <ul style="list-style-type: none"> • Positive view of self in the context of lay referral • Positive view of other in the context of lay referral • Positive view of self in the context of healthcare consultation • Positive view of other in the context of healthcare consultation |
| Preoccupied template | <ul style="list-style-type: none"> • Negative view of self in the context of lay referral • Positive view of other in the context of lay referral |

| | |
|---|--|
| Adult Attachment Style (placeholder codes) | <i>A Priori</i> Themes Based Upon a Concept of Self and Other <ul style="list-style-type: none"> Negative view of self in the context of healthcare consultation Positive view of other in the context of healthcare consultation |
| Dismissing template | <ul style="list-style-type: none"> Positive view of self in the context of lay referral Negative view of other in the context of lay referral Positive view of self in the context of healthcare consultation Negative view of other in the context of healthcare consultation |
| Fearful-avoidant template | <ul style="list-style-type: none"> Negative view of self in the context of lay referral Negative view of other in the context of lay referral Negative view of self in the context of healthcare consultation Negative view of other in the context of healthcare consultation |

NOTE 7: There has been much theoretical development with regard to adult attachment styles. Underpinning each of the four different adult attachment styles are two dimensions- the model of self and model of others, although the two dimensions are also referred to as 'anxiety' and 'avoidance' in the context of the quantitative ECR scale. Here, it is important to acknowledge the conceptual differences between the models whilst also recognising how they are interconnected. For the purpose of this study design, the focus is not the examination, nor the validity of dimensions across the models, but to use the existing methods and concepts to extend our understanding of how attachment theory may offer explanatory value in terms of illness behaviour.

Based upon this intention is that the ECR is pragmatically employed as a means of organising the data whilst the Bartholomew model informed the foundation of a priori themes. This is because the Bartholomew model appeared to offer a broader relational conceptual basis that could be applied in the context of lay referral. However, it is acknowledged that the priori of themes as outlined in this study design, will undergo much further development, and the conceptual dimensions if perceived as helpful in relation to the data may be interchangeably drawn upon or omitted (as discussed in the results and discussion section of chapter five).

Stages of Template Analysis (King and Brooks, 2018)

Table 5.5 described some of the details and stages of template analysis which took place as part of this study.

Table 5.5

Stages and Details of Template Analysis

| Stage | Details of the Stages |
|---|---|
| Familiarisation of the data | Each set of data was read and re-read. The researcher read the whole data set for each group. Time was invested at this stage and considered to aid the analysis process. |
| Preliminary coding of the data in conjunction with the <i>a priori</i> themes | Identified any text that appeared to be helpful or to add value to the topic of lay referral and help-seeking behaviour on a sub-set. |

| Stage | Details of the Stages |
|---|--|
| The development of the coding template which built upon the <i>a priori</i> themes | <p>Highlighted areas of interest and made notes. In conjunction with the <i>a priori</i> of themes and preliminary comments, themes were developed. A process of clustering took place bringing together the themes.</p> <p>Template formulation took place and an emphasis was placed upon hierarchical coding (similar codes clustered to create more general higher or top level ordered themes).</p> |
| The initial template was applied, adapted and developed as necessary | <p>The initial template was applied to the overall data set, the identification of sections relevant to the research question highlighted and coded. These sections were considered in light of the initial template, when they did not, the template was developed. Changes to the template included, adaption of themes, new themes, redefining of themes, and the removal of themes.</p> |
| Repeated for each of the groups | <p>The process was repeated four times for each of the adult attachment style groups</p> |
| Each of the final templates formed the foundation of interpretation and guided the research write-up. | |

Quality Checks

For more information in reference to the quality checks used as part of this study please see Chapter two.

Quantitative Results Section

Descriptive Statistics

Participant Demographics. Ninety-four participants (76 female, 17 males, 1 gender not reported) over the age of 18 years old (coded by life stage, and categorised into under 25 years and over) took part in this study. The sample consisted of adults who had self-reported the experience of physical bodily changes and/ or illness symptoms within the previous three months. The participants' main place of residency included the United Kingdom, Europe, The Isle of Man, and Canada. Table 5.6 indicates the overall sample demographics.

Table 5.6

Overall Sample Participant Demographics

| Variable | Overall Sample % | Overall Sample N |
|---|------------------|------------------|
| Participants (N) | | 94 |
| Life stage | | |
| Late adolescence, early/ young adulthood (25 years and under) | 73.4 | 69 |
| Young, middle, older, late adulthood (25 years and over) | 26.6 | 25 |
| Gender * | | |
| Female | 81.7 | 76 |
| Male | 18.3 | 17 |
| Marital status * | | |
| Single (never married) | 81.7 | 76 |
| Married or domestic partnerships | 12.9 | 12 |

| Variable | Overall Sample % | Overall Sample N |
|---|------------------------|------------------------|
| Separated | 1.1 | 1 |
| Divorced | 3.2 | 3 |
| Widowed | 1.1 | 1 |
| Household composition * | | |
| Partner | | |
| Yes | 36.6 | 12 |
| No | 63.4 | 82 |
| Children under the age of 18 years | | |
| Yes | 12.8 | 12 |
| No | 87.2 | 82 |
| Children living in the participants' home | | |
| Yes | 18.0 | 16 |
| No | 76.4 | 68 |
| Other | 5.6 | 5 |
| Education * | | |
| Less than high school | 1.1 | 1 |
| High school or equivalent | 26.9 | 25 |
| Some college but no degree | 55.9 | 52 |
| Bachelor degree | 7.5 | 7 |
| Post graduate degree | 8.6 | 8 |
| Engaged with lay referral | 91.2 | 84 |
| Did not engage with lay referral | 8.8 | 8 |
| Engaged with healthcare services | 51.6 | 68 |
| Did not engage with healthcare services | 48.4 | 28 |

Note. *% of those reported

Personal Factors and Situational Stimuli

Descriptive Statistics

The self-reported pre-existing health conditions which encompassed a variation of illness experiences across both physical and mental health can be seen in table 5.7. It is noted that over half (61.7%) of the sample reported an existing health condition(s), but over a third did not.

Table 5.7

Overall Sample; Self-Reported Existing Illness or Health Conditions

| Existing Illness or health condition | Number of Self-Reports (N) * | Percentage % |
|--|---------------------------------|-----------------|
| Physical health | 23 | 24.5 |
| Mental health | 9 | 9.6 |
| Physical and mental health | 7 | 7.4 |
| Unspecified illness or health condition | 19 | 20.2 |
| Reported no existing illness or health condition | 36 | 38.3 |

Note. *The category of mental health encompassed specific learning disabilities.

Table 5.8 shows that one third of the sample self-reported scores within the fearful-avoidant attachment style with reasonably similar numbers in the other three styles.

Table 5.8*Overall Sample Description; Adult Attachment Style*

| Adult Attachment style | Number of Participants per Group (N) | Percentage of the Participants per Adult Attachment Style % |
|------------------------|--|--|
| Secure | 18 | 19.4 |
| Dismissing | 22 | 23.7 |
| Preoccupied | 23 | 24.7 |
| Fearful-avoidant | 30 | 32.3 |

Personal Factors, Cognitive Illness Representations, and Social Coping Responses

Gender Distributions and Attachment Style

A 2 x 4 chi-square test for association was run to assess whether gender (female/ male) influenced attachment style group membership (secure, preoccupied, dismissing, fearful-avoidant). A non-significant association between gender and adult attachment style $\chi^2(3) = 2.558$, $p = .465$ was found i.e., adult attachment style was independent of gender.

Table 5.9*Crosstabulation for Gender and Adult Attachment Style (N (Expected N))*

| | Secure Attachment | Dismissing Attachment | Preoccupied Attachment | Fearful- Attachment |
|--------|----------------------|--------------------------|---------------------------|------------------------|
| Female | 20.3% N= 15 | 20.3% N= 15 | 24.3% N= 18 | 35.1% N= 26 |

| | | | | |
|------|--------|-------|--------|--------|
| | (13.8) | 17.1) | (18.7) | (24.4) |
| Male | 11.8% | 35.0% | 24.9% | 23.5% |
| | N=2 | N= 6 | N= 5 | N=4 |
| | (3.2) | (3.9) | (4.3) | (5.6) |

Gender and Illness Perceptions

A series of Mann-Whitney U Tests were run to determine the effect of gender (male/ female) upon each of the 8 domains of the BIPQ. There was no statistically significant difference between the BIPQ domains scores between females and males (see Table 5.10).

Table 5.10*Test of Gender Differences in BIPQ Scores*

| BIPQ domains | Overall | | Female | | Male | | Mann-Whitney (<i>p</i>) |
|--------------------------|----------|-----------|----------|-----------|----------|-----------|---------------------------|
| | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> | |
| Consequence | 5.47 | 2.842 | 5.38 | 2.822 | 5.29 | 2.801 | .967 |
| Timeline | 6.10 | 3.514 | 6.04 | 3.434 | 5.82 | 3.925 | .802 |
| Personal control | 5.73 | 2.791 | 5.65 | 2.625 | 5.82 | 3.358 | .906 |
| Treatment control | 6.53 | 2.965 | 6.50 | 2.971 | 6.35 | 3.061 | .818 |
| Identity | 5.84 | 2.717 | 5.85 | 2.610 | 5.35 | 3.040 | .552 |
| Illness concern | 4.93 | 2.945 | 4.88 | 2.804 | 4.71 | 3.255 | .790 |
| Coherence | 7.47 | 2.865 | 7.22 | 2.815 | 8.24 | 3.073 | .135 |
| Emotional representation | 6.35 | 3.144 | 6.39 | 3.001 | 6.06 | 3.766 | .810 |

Gender and Lay Referral

A 2 x 2 chi-square test for association was conducted to examine whether gender affected distribution with regards to self-reported engagement with lay referral (yes/ no). A significant association between gender and lay referral ($\chi^2(1) = 5.547$, $p = .039$) was found. Through an examination of actual vs expected N, fewer females than expected did not engage with lay referral and more than expected did; and the converse for male participants.

Table 5.11

Crosstabulation for Gender and Lay Referral (N (Expected N), Fishers Exact)

| | Engaged with Lay Referral | Did Not Engage with Lay Referral |
|--------|---------------------------|----------------------------------|
| Female | 94.5% N= 69 (66.5) | 5.5% N= 4 (6.5) |
| Male | 76.5% N=13 (15.5) | 23.5% N= 4 (1.5) |

Gender and Help-seeking Behaviour in the Context of Professional Healthcare Services

A 2 x 2 chi-square test for association was conducted to examine whether gender (female/ male) affected self-reported engagement with seeking professional healthcare advice (yes/ no) and as seen in Table 5.12 a non-significant association was found ($\chi^2(1) = .205$, $p = .651$) meaning that help-seeking behaviour was independent of gender.

Table 5.12

Crosstabulation for Gender and HCP (N (Expected), Pearson Chi-Square)

| | Engaged with HCP | Did Not Engage with HCP |
|--------|--------------------------|--------------------------|
| Female | 50.0% N= 36 (36.8) | 50.0% N= 36 (35.2) |
| Male | 56.3% N=9 (8.2) | 43.8% N= 7 (7.8) |

Personal Factors, Cognitive Illness Representations, and Social Coping Responses

Life Stage and Attachment Style

A 2 x 4 chi-square test for association was conducted to establish whether life stage (late adolescence, early/ young adulthood and young, middle, older/ late adulthood) was associated with the attachment style groups (secure, preoccupied, dismissing, fearful-avoidant). A non-statistically significant association between life stage and adult attachment style ($\chi^2(3) = 5.883, p = .117$) suggesting that attachment style was independent of life stage.

Table 5.13

*Crosstabulation Percentages for Life Stage and Adult Attachment Style (N
(Expected))*

| | Secure Attachment | Dismissing Attachment | Preoccupied Attachment | Fearful- avoidant Attachment |
|---|-------------------------|--------------------------|---------------------------|------------------------------------|
| Late adolescence, early/ young adulthood | 17.4% N=12 (13.4) | 18.8% N=13 (16.3) | 26.1% N=18 (17.1) | 37.7% N=26 (22.3) |
| Young, middle, older/ late adulthood | 25.0% N=6 (4.6) | 37.5% N=9 (5.7) | 20.8% N=5 (5.9) | 16.7% N=4 (7.7) |

Life Stage and Illness Perceptions

A series of Mann-Whitney U Tests were run to determine the effect of life stage (late adolescence, early/ young adulthood and young, middle, older/ late adulthood) on each of the 8 domains of the BIPQ. There was no statistically significant difference between the BIPQ domain scores between the life stage groups (see table 5.14).

Table 5.14*Illness Perceptions and Life Stage*

| BIPQ Domains | Late Adolescence, Early/ Young Adulthood | | Young, Middle, Older/ Late Adulthood | | Mann-Whitney U Tests (<i>p</i>) |
|--------------------------|---|-----------|---|-----------|-----------------------------------|
| | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> | |
| Timeline | 6.13 | 3.338 | 5.79 | 3.978 | .717 |
| Personal control | 5.43 | 2.587 | 6.38 | 3.132 | .671 |
| Treatment control | 6.20 | 2.878 | 7.29 | 3.043 | .164 |
| Identity | 5.87 | 2.526 | 5.54 | 3.120 | .134 |
| Coherence | 7.25 | 2.892 | 7.96 | 2.742 | .560 |
| Illness concern | 4.75 | 2.654 | 5.17 | 3.535 | .714 |
| Emotional representation | 6.54 | 3.042 | 5.63 | 3.321 | .326 |
| Consequence | 5.35 | 2.703 | 5.58 | 3.106 | .239 |

Life Stage and Lay Referral

A 2 x 2 chi-square test for association was conducted to examine whether life stage affected self-reported engagement with lay referral (yes/ no). A non-significant association between life stage and lay referral $\chi^2 (1) = .000, p = .985$ was found suggesting that lay referral was independent of life stage.

Table 5.15

The Effect of Life Stage Upon Lay Referral (N (Expected) Fisher's Exact)

| | Engaged with Lay Referral | Did Not Engage with Lay Referral |
|---|---------------------------|----------------------------------|
| Late adolescence, early/ young adulthood | 91.2% N=62 (62.0) | 8.8% N=6 (6.0) |
| Young, middle, older/ late adulthood | 91.3% N=21 (21.0) | 8.7% N=2 (2.0) |

Life Stage and Help-seeking Behaviour

A 2 x 2 chi-square test for association was conducted between life stage, and self-reported help-seeking in the context of professional healthcare advice (yes/ no). A non-statistically significant association between life stage and help-seeking $\chi^2 (1) = .014, p = .906$ thus help-seeking was independent of life stage.

Table 5.16

The Effect of Life Stage Upon Help-Seeking Behaviour (N (Expected) Pearson Chi-Square)

| | Engaged with HCP | Did Not Engage with HCP |
|---|-------------------------|-------------------------|
| Late adolescence, early/ young adulthood | 50.7% N=34 (34.2) | 49.3% N=33 (32.8) |
| Young, middle, older/ late adulthood | 52.2% N=12 (11.8) | 47.8% N=11 (11.2) |

Social Coping Responses and Help-seeking Behaviour

The Direction of Lay Referral and Help-seeking Behaviour

To examine whether those who engaged with lay referral and were advised to consult for HCP advice by the lay referent, went onto consult for HCP more often than participants who did not use their lay referral network; a x 2 chi-square test for association was conducted. The results indicated a significant association between lay referees' advice to consult and the participants' help-seeking behaviour ($\chi^2(1) = 17.015, p = .000$) whereby, on examination of the actual vs observed frequencies it appeared that those who had engaged in lay referral and were advised to seek HCP advice did so more than expected, compared to those whose lay referees did not make such a suggestion. This indicating that lay referral influenced help-seeking.

Table 5.17*Crosstabulation for the Direction of Lay Referral and Help-Seeking (N (Expected))*

| | Lay Referee Suggested HCP Advice | Lay Referee Did Not Suggest HCP Advice |
|---|-------------------------------------|---|
| The participant sought healthcare advice | | |
| Yes | 75.6% N=34 (24) | 21.0% N=11 (21) |
| No | 30.2% N=13 (23) | 69.8% N=30 (20) |

Exploratory Analysis; Personal Factors, Cognitive Representations, and Social Coping Responses

The participants' illness perceptions have been explored to investigate how illness schemas, and pre-existing health conditions may influence the key variables of lay referral, and help-seeking behaviour. Further theoretically oriented exploratory analysis in alignment with the research project's objectives was conducted in terms of adult attachment, illness perceptions, and the participant's sense of health threat in relation to their bodily changes, lay referral, and help-seeking behaviour.

Pre-existing Health Conditions and Illness Perceptions

Eight Kruskal-Wallis tests were conducted to determine if a statistically significant difference existed between the participants who self-reported existing health conditions (pre-existing health condition) (61.7%)/ none reported (38.8%) and illness perceptions (i.e. eight BIPQ domains). A significant difference was found between the two groups for the domains of consequence $\chi^2(1) = 12.127, p=.000$; timeline $\chi^2(1) = 12.019, p=.001$; identity $\chi^2(1) = 13.835, p=.000$; illness concern $\chi^2(1) = 6.145,$

$p=.013$; and emotional representation $\chi^2(1) = 4.396$, $p=.036$. In each case the means of those with a pre-existing condition were higher. There was no effect of pre-existing condition on personal or treatment control beliefs nor on the participant's sense of illness coherence.

Table 5.18

Illness Perceptions and Pre-Existing Health Conditions

| BIPQ | Mean Rank | | Kruskal-Wallis (<i>P</i>) |
|--------------------------|---|----------------------------------|--------------------------------|
| | Pre-existing health condition (<i>N</i> =58) | None reported (<i>N</i> =36) | |
| Perceived consequence | 54.22 | 34.49 | .000* |
| Timeline | 54.66 | 34.88 | .001* |
| Personal control | 45.83 | 48.83 | .598 |
| Treatment control | 43.38 | 52.74 | .101 |
| Identity | 55.22 | 33.99 | .000* |
| Illness concern | 52.47 | 38.33 | .013* |
| Coherence | 46.52 | 47.76 | .827 |
| Emotional representation | 51.64 | 39.65 | .036* |

* $p<.05$

Illness Perceptions and Lay Referral

A series of Mann-Whitney U Tests determined whether illness perceptions affected self-reported engagement with lay referral. Only the domain of timeline demonstrated a significant effect ($p=.031$) with a rank mean difference between those who self-reported to engage with lay referral (47.84) and those who reported that they did not (26.88). Those who perceived their bodily changes to likely be more permanent than temporary or that the bodily changes may last for a prolonged period of time engaged more with lay referral.

Table 5.19*Illness Perceptions and Lay Referral*

| BIPQ domains | Engaged with Lay Referral | | Did Not Engage with Lay Referral | | Mann-Whitney (<i>p</i>) | Mean Rank / Engaged with Lay Referral | Mean Rank/ Did Not Engage with Lay Referral |
|--------------------------|---------------------------|-----------|----------------------------------|-----------|---------------------------|---------------------------------------|---|
| | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> | | | |
| Timeline | 6.20 | 3.481 | 3.38 | 2.387 | .031* | 47.84 | 26.88 |
| Personal control | 5.76 | 2.748 | 5.13 | 3.091 | .477 | 46.61 | 39.69 |
| Treatment control | 6.58 | 2.889 | 5.88 | 3.834 | .592 | 46.46 | 41.25 |
| Identity | 5.83 | 2.650 | 4.88 | 3.091 | .442 | 46.66 | 39.19 |
| Coherence | 7.52 | 2.795 | 7.00 | 3.703 | .713 | 46.31 | 42.75 |
| Illness concern | 4.92 | 2.889 | 3.88 | 2.900 | .344 | 46.81 | 37.63 |
| Emotional representation | 6.35 | 3.074 | 5.38 | 3.926 | .422 | 46.69 | 38.88 |
| Consequence | 5.44 | 2.772 | 4.75 | 3.240 | .471 | 46.12 | 39.19 |

**p* < .05

Illness Perceptions and Help-seeking Behaviour in the Context of Healthcare Professional Advice

A series of Mann-Whitney U Tests were run to determine the effect of illness perceptions (i.e.- the eight BIPQ domains) on self-reported engagement with professional healthcare services or advice. No significant differences were found between the groups HCP engagement behaviour in relation to illness representations.

Table 5.20*Illness Perceptions and HCP Engagement*

| BIPQ Domains | HCP Engagement | | No HCP Engagement | | Mann-Whitney (<i>p</i>) |
|--------------------------|----------------|-----------|-------------------|-----------|------------------------------|
| | <i>M</i> | <i>SD</i> | <i>M</i> | <i>SD</i> | |
| Timeline | 6.52 | 3.698 | 5.70 | 3.289 | .243 |
| Personal control | 5.70 | 2.707 | 5.55 | 2.782 | .792 |
| Treatment control | 6.83 | 3.057 | 5.59 | 2.778 | .162 |
| Identity | 6.20 | 2.697 | 5.45 | 2.592 | .160 |
| Coherence | 7.57 | 3.110 | 7.23 | 2.605 | .339 |
| Illness concern | 5.30 | 3.003 | 4.36 | 2.605 | .108 |
| Emotional representation | 6.54 | 3.103 | 6.05 | 3.080 | .410 |
| Consequence | 5.84 | 2.738 | 5.05 | 2.770 | .154 |

Exploratory Analysis; Adult Attachment Style, Illness Perceptions, Perceived Threat, Lay Referral, and Help-seeking

Adult Attachment Style and Illness Perceptions

Eight Kruskal-Wallis tests were conducted to determine if a statistically significant difference existed between the different adult attachment style groups in regard to illness perceptions (i.e., eight BIPQ domains). A trend towards significance was found in terms of perceived consequence ($p=.067$) and a significant difference was seen with regard to emotional representation between adult attachment style groups ($p=.032$). The post hoc pairwise Bonferroni was examined although no significant difference was found, this led to an additional Mann-Witney in terms of emotional representation and adult attachment theory. No significance was found; therefore, the results are interpreted with caution. However, when considering the mean scores, the fearful-avoidant adult attachment mean score (6.37) was higher than the secure adult attachment style group (4.19) in reference to perceived consequence $p=.067$ is not significant although a trend towards it only; and the fearful-avoidant adult attachment mean score (7.00) was higher than the secure adult attachment style group (5.12) in relation to emotional representations.

Table 5.21*Attachment Style and Illness Perceptions*

| BIPQ | Mean | | | | Kruskal-Wallis (<i>p</i>) |
|--------------------------|----------------------|--------------------------|---------------------------|--------------------------------|--------------------------------|
| | Secure Attachment | Dismissing Attachment | Preoccupied Attachment | Fearful-avoidant Attachment | |
| Perceived consequence | 4.19 | 4.62 | 5.57 | 6.37 | .067 [^] |
| Timeline | 4.88 | 5.62 | 7.17 | 6.00 | .227 |
| Personal control | 6.65 | 6.10 | 5.65 | 4.87 | .243 |
| Treatment control | 6.82 | 6.76 | 6.70 | 5.90 | .679 |
| Identity | 5.24 | 5.38 | 5.78 | 6.30 | .633 |
| Illness concern | 4.29 | 4.10 | 5.22 | 5.40 | .274 |
| Coherence | 8.53 | 7.29 | 7.48 | 6.80 | .194 |
| Emotional representation | 5.12 | 5.29 | 7.30 | 7.00 | .032 [*] |

^{*}*p*<.05, [^] non sig. trend

Adult Attachment Style and How Illness and/ or Bodily Changes were Perceived as Threatening or Benign in terms of the BIPQ

Table 5.22 outlines the overall sample mean rank generated through a Kruskal-Wallis Test in regards to adult attachment style and the perceived threat of the participants' bodily changes. The higher the mean score (0-100), the greater the perceived health threat. As shown, the secure adult attachment style group reported lowest perceived threat; with the fearful-avoidant and preoccupied adult attachment style groups reporting a higher perceived threat. However, all subgroup means reflect only a moderate health threat in connection to the experience of bodily changes, with no statistically significant difference in perceived threat scores between the groups ($\chi^2 (3) = 4.424, p = .219$).

Table 5.22

Perceived Health Threat (BIPQ) and Adult Attachment Style

| Secure Mean BIPQ Score | Dismissing Mean BIPQ Score | Preoccupied Mean BIPQ Score | Fearful-avoidant Mean BIPQ Score |
|------------------------------|----------------------------------|-----------------------------------|--|
| 38.75 | 41.61 | 52.54 | 51.65 |

Note. Self-reported mean BIPQ score 0-100 (100 = increased perceived health threat)

Adult Attachment Style and Lay Referral

In order to address the question of whether adult attachment style groups (secure, preoccupied, dismissing, and fearful-avoidant) had any association with self-reported engagement with lay referral, a 4 x 2 chi-square test was conducted. A non-statistically significant association between adult attachment style and engagement with lay referral ($\chi^2 (3) = 4.898, p = .179$) was found.

Table 5.23

Crosstabulation Percentages for Adult Attachment Style and Engagement with Lay Referral (N (Expected N))

| Adult Attachment Style Group | Self-Reported Engagement; Lay Referral | Self-Reported Non-Engagement; Lay Referral |
|---------------------------------|---|--|
| Secure | 88.2% N=15 (15.5) | 11.8% N=2 (1.5) |
| Dismissing | 90.9% N=20 (20.1) | 9.1% N=2 (1.9) |
| Preoccupied | 100% N=22 (21.0) | 0.0% N=0 (1.9) |
| Fearful-avoidant | 86.7% N=26 (27.4) | 13.3% N=4 (2.6) |

Adult Attachment Style and Help-seeking Behaviour

A 4 x 2 chi-square test for association also examined the relationship between adult attachment style groups (secure, preoccupied, dismissing, and fearful-avoidant) and self-reported help-seeking behaviour in the context of healthcare professional advice. A non-statistically significant association between adult attachment style and help-seeking behaviour was found $\chi^2 (3) = 1.245, p = .742$.

Table 5.24

Crosstabulation Percentages for Adult Attachment Style and Help-Seeking Behaviour in the Context of Healthcare Professional Advice (N (Expected N))

| Adult Attachment Style Group | Self-Reported Engagement; HCP | Self-Reported Non- Engagement; HCP |
|------------------------------|----------------------------------|---------------------------------------|
| Secure | 47.1% N=8 (8.7) | 52.9% N=9 (8.3) |
| Dismissing | 50.0% N=11 (11.2) | 50% N=11 (10.8) |
| Preoccupied | 60.9% N=14 (11.8) | 39.1% N=9 (11.2) |
| Fearful-avoidant | 46.6% N=13 (14.3) | 53.6% N=15 (13.7) |

Predicting Lay Referral Behaviour using Logistic Regression

An exploratory, theoretically informed hierarchical logistic regression was conducted due to the dichotomous dependent variable. This explored the probability of engagement with lay referral (the dependant variable) based on a selection of personal factors (gender, pre-existing health conditions, attachment style), and cognitive representations (illness perceptions associated with the domains of consequence, timeline, identity, illness concern and emotional representation) (the independent variables) relevant to the theoretically orientated research question and existing health psychology theory CSM. The overall regression model explained 27% of the variance however this was non-significant $\chi^2(10) = 10.667$, $p = .384$ therefore, the results were interpreted with caution. Out of all of the independent variables, only

one (gender) demonstrated a trend ($p=.055$) as explored in the above previous analysis- whereby females consult more than males.

Table 5.25*Lay Referral Logistic Regression*

| Variable | | B | SE | P | Odd Ratios | 95% C.I for EXP (B) | |
|----------|-------------------------------|---------|----------|-------|------------|---------------------|--------|
| | | | | | | Lower | Upper |
| Step 1 | Gender | 1.403 | .833 | .092 | 4.068 | .795 | 20.815 |
| | Pre-existing health condition | -.816 | .816 | .318 | .442 | .089 | 2.191 |
| Step 2 | Gender | 1.855 | .947 | .050 | 6.394 | 1.000 | 40.883 |
| | Pre-existing health condition | -.665 | .954 | .485 | .514 | .079 | 3.332 |
| | Secure attachment | .200 | 1.116 | .857 | 1.222 | .137 | 10.879 |
| | Dismissing attachment | -.763 | 1.134 | .501 | .466 | .050 | 4.309 |
| | Preoccupied attachment | -19.31 | 8157.82 | .998 | .000 | .000 | |
| Step 3 | Gender | 2.092 | 1.090 | .055^ | 8.097 | 9.57 | 68.543 |
| | Pre-existing health condition | -.966 | 1.026 | .346 | .381 | .051 | 2.942 |
| | Secure attachment | .881 | 1.334 | .509 | 2.414 | .177 | 32.953 |
| | Dismissing attachment | -.464 | 1.289 | .719 | .629 | .050 | 7.859 |
| | Preoccupied attachment | -19.162 | 7983.249 | .998 | .000 | .000 | |
| | Consequence | .295 | .345 | .392 | 1.344 | .684 | 2.640 |

| Variable | <i>B</i> | SE | <i>P</i> | Odd Ratios | 95% C.I for EXP (B) | |
|--------------------------|----------|------|----------|------------|---------------------|-------|
| | | | | | Lower | Upper |
| Timeline | .074 | .207 | .719 | .928 | .619 | 1.392 |
| Identity | -.160 | .234 | .496 | .852 | .538 | 1.350 |
| Illness concern | -.095 | .312 | .761 | .909 | .493 | 1.678 |
| Emotional representation | .198 | .226 | .381 | 1.219 | .783 | 1.900 |

Note. The Nagelkerke R^2 for step 1 was = 0.92, step 2 = 2.17, step 3= .269. ^ non sig. trend.

Help-seeking in the Context of Professional Healthcare Advice; Logistic Regression

An exploratory and theoretically informed hierarchical logistic regression was run to explore the probability of help-seeking behaviour in the context of professional healthcare advice (the dependant variable) based on a selection of personal factors (gender, pre-existing health conditions, attachment style), cognitive representations (illness perceptions associated with the domains of consequence, timeline, identity, illness concern and emotional representation) and lay referral (the independent variables) relevant to the theoretically orientated research question and existing health psychology theory CSM. The overall regression model explained a small 11% of the variance and was non-significant $\chi^2(11) = 7.010$, $p = .798$.

Table 5.26*Help-Seeking in the Context of Professional Healthcare Advice; Logistic Regression*

| Variable | | <i>B</i> | SE | <i>P</i> | Odd Ratios | 95% C.I for EXP (<i>B</i>) | |
|----------|-------------------------------|----------|------|----------|------------|------------------------------|-------|
| | | | | | | Lower | Upper |
| Step 1 | Gender | -.220 | .572 | .701 | .803 | .262 | 2.462 |
| | Pre-existing health condition | -.012 | .448 | .979 | .988 | .411 | 2.379 |
| Step 2 | Gender | -.049 | .594 | .934 | .952 | .297 | 3.050 |
| | Pre-existing health condition | .398 | .710 | .830 | 1.110 | .427 | 2.884 |
| | Secure attachment | .398 | .710 | .575 | 1.488 | .370 | 5.980 |
| | Dismissing attachment | .279 | .609 | .647 | .756 | .229 | 2.498 |
| | Preoccupied attachment | -.591 | .584 | .312 | .554 | .176 | 1.739 |
| Step 3 | Gender | -.091 | .615 | .882 | .913 | .274 | 3.046 |
| | Pre-existing health condition | .412 | .542 | .447 | 1.509 | .522 | 4.364 |

| | Variable | <i>B</i> | SE | <i>P</i> | Odd Ratios | 95% C.I for EXP (B) | |
|--------|-------------------------------|----------|------|----------|------------|---------------------|-------|
| | | | | | | Lower | Upper |
| Step 4 | Secure attachment | .377 | .750 | .616 | 1.457 | .335 | 6.340 |
| | Dismissing attachment | -.401 | .650 | .538 | .670 | .187 | 2.396 |
| | Preoccupied attachment | -.789 | .633 | .207 | .450 | .130 | 1.555 |
| | Consequence | -.057 | .157 | .717 | .945 | .694 | 1.285 |
| | Timeline | .079 | .098 | .419 | 1.082 | .893 | 1.312 |
| | Identity | -.059 | .123 | .631 | .943 | .741 | 1.199 |
| | Illness concern | -.151 | .153 | .324 | .860 | .638 | 1.160 |
| | Emotional representation | .057 | .107 | .591 | 1.059 | .859 | 1.306 |
| | Gender | -.190 | .634 | .764 | .827 | .239 | 2.867 |
| | Pre-existing health condition | .390 | .546 | .474 | 1.478 | .507 | 4.305 |
| | Secure attachment | .330 | .757 | .663 | 1.391 | .316 | 6.128 |
| | Dismissing attachment | -.465 | .660 | .481 | .628 | .172 | 2.292 |

| Variable | <i>B</i> | SE | <i>P</i> | Odd Ratios | 95% C.I for EXP (B) | |
|--------------------------|----------|-------|----------|------------|---------------------|--------|
| | | | | | Lower | Upper |
| Preoccupied attachment | -.712 | .640 | .266 | .490 | .140 | 1.720 |
| Consequence | -.078 | .159 | .621 | .925 | .677 | 1.262 |
| Timeline | .074 | .098 | .452 | 1.077 | .888 | 1.305 |
| Identity | -.051 | .123 | .680 | .951 | .748 | 1.209 |
| Illness concern | -.131 | .154 | .393 | .877 | .649 | 1.185 |
| Emotional representation | .049 | .107 | .648 | 1.050 | .851 | 1.296 |
| Lay referral | 1.418 | 1.221 | .245 | 4.128 | .377 | 45.169 |

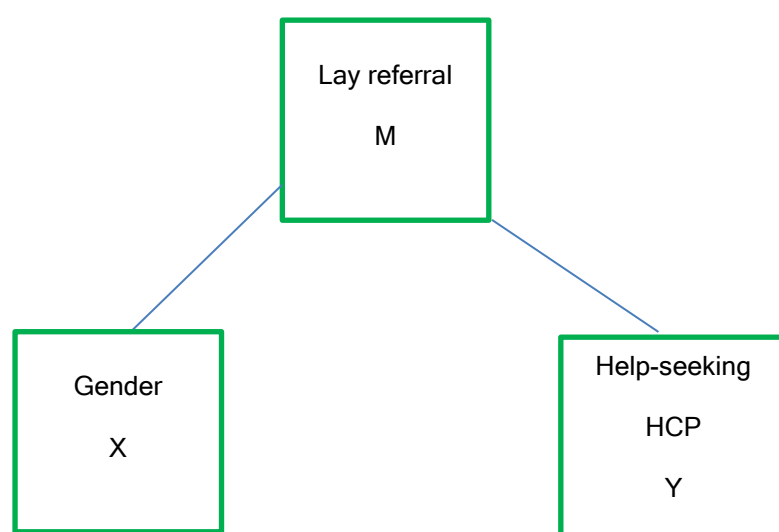
Note. The Nagelkerke R^2 for step 1 was = 0.002, step 2 = .036, step 3= .083, step 4= .107

Mediation Analysis

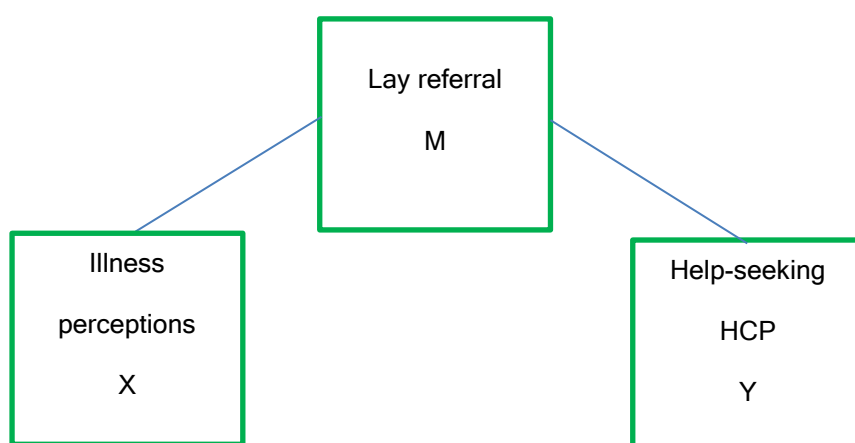
Mediation analysis was considered as part of the analysis however the assumptions (Baron & Kenney, 1986) were not met –although based upon the previous analysis the below has been mapped, see figure 5.9.

Figure 5.9

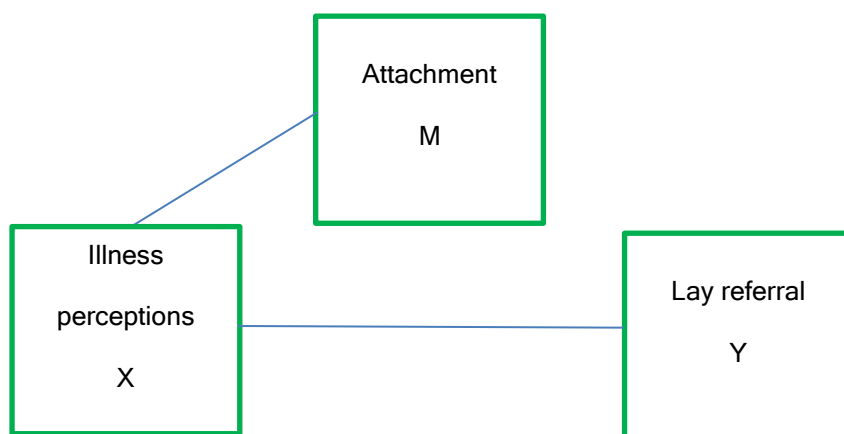
Mediation Analysis Variables



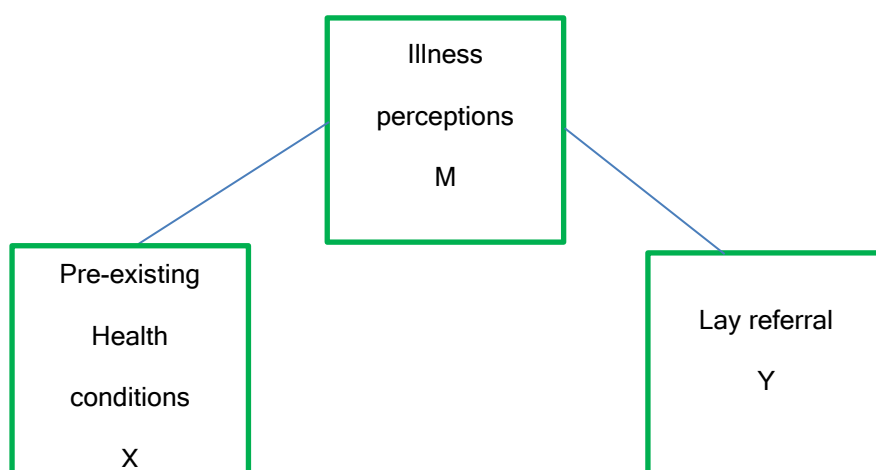
Note. relationships were found between gender /lay referral, and also between lay referral/ help-seeking. No relationship was found between gender/ help-seeking.



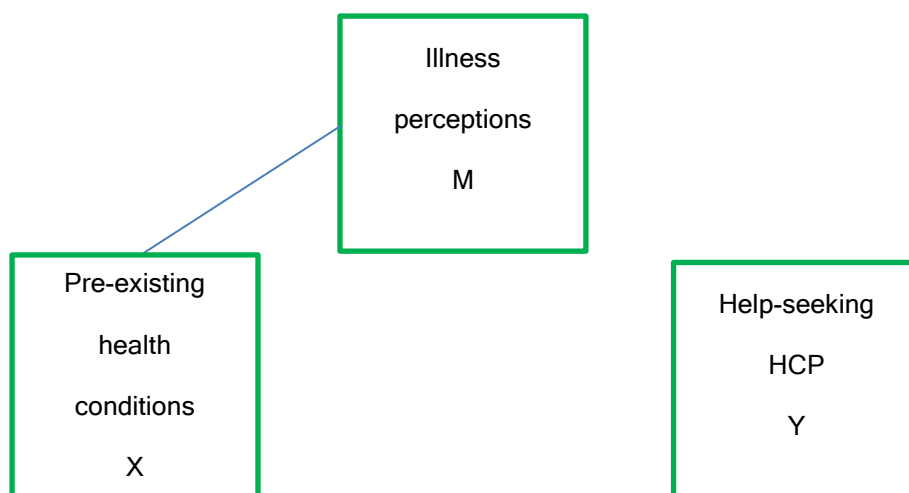
Note. relationships were found between Illness perceptions / lay referral, and between lay referral and help-seeking. No relationship was found between illness perceptions and help-seeking.



Note. relationships were found between Illness perceptions / attachment and between illness perceptions and lay referral. No relationship was found between attachment and lay referral.



Note. relationships between pre-existing health conditions and illness perceptions were found and between illness perceptions and lay referral. No relationship was found between pre-existing health conditions and attachment and lay referral.



Note. a relationship between pre-existing health conditions and illness perceptions was found although no relationship between illness perceptions / HCP nor pre-existing health conditions/ HCP.

Qualitative Results Section

An Adult Attachment Theory Perspective of Lay Referral in the Context of the COVID-19 Pandemic

The final templates for each adult attachment style group are presented in this section. These all relate to whether the outbreak of COVID-19 changed who (if anyone) the participants spoke to about their bodily changes and/or illness symptoms (or not) and why. The abductive themes were generated through a template analysis which used a hard *a priori* set of themes built on adult attachment theory and focused on relational representations and schemas, the model of self and other (Bartholomew, 1990). This was based upon the contemporary development of lay referral as discussed in Chapter four, that indicated that these constructs are considered to be the constituent elements of lay referral. This gave insight to how participants who self-reported different adult attachment styles experienced on occasion both perceptual difference and similarities in terms of the social coping process of lay referral following the recognition of bodily changes. This abductive analysis offers insight into how adult attachment style shapes lay referral.

The final template included several higher level themes, the higher level main theme for the secure adult attachment style group was *‘responsive and reciprocal lay referral’*; for the dismissing adult attachment style group it was *‘typical lay referral engagement and relational affect disengagement’*; for the preoccupied adult attachment style group *‘divergent self and other perceptions; the experience of lay referral’* and for the fearful-avoidant adult attachment style group *‘decreased fearful avoidance and increased hypervigilance of lay referral’*. Each of the higher-level themes included lower-level themes which are outlined below in the final template for each of the different adult attachment style groups.

Final Template Created as part of the Analytical Strategy for each of the Adult Attachment Style Groups

Lay Referral; the Secure Adult Attachment Style Group

1. Responsive and reciprocal lay referral

- 1.1 Positively views the self as typically actively engaging with, or increasing lay referral with close others
- 1.2 Positively views others as responsive; regulatory lay referral and making sense
- 1.3 Positively views self as responsive to others’ needs in a pandemic and lay referral

Lay Referral; the Dismissing Adult Attachment Style Group

2. Typical lay referral engagement and relational affect disengagement

- 2.1 Positively views the self as actively engaging with lay referral
- 2.2 Decreased lay referral; negative view of others and relational affect

Lay Referral; the Preoccupied Adult Attachment Style Group

3. Divergent self and other perceptions; the experience of lay referral

- 3.1 Anticipated negative perceptions of others in relation to the self; decreased and avoidant lay referral
- 3.2 Positively views others as responsive; affect-regulation, lay referral and making sense

Lay Referral; the Fearful-Avoidant Adult Attachment Style Group

4. Decreased fearful avoidance and hypervigilance of lay referral

- 4.1 Lay referral; negative view of the interpersonal self
- 4.2 Health related fear for others, hypervigilance, and help-seeking
- 4.3 Negative view of others, decreased lay referral, fear of isolation and separation

Qualitative Results

The Secure Adult Attachment Style Group

1. Responsive and Reciprocal Lay Referral. The main theme of '*responsive and reciprocal lay referral*' generated through the secure adult attachment style group gave narrative context to the participants' perceptions and experiences. The participants expressed a sense of continuous, typical, and actively increased engagement with lay referral. Participants wrote about not only engaging with lay referral in terms of their own bodily changes, but also on how the social coping process of lay referral facilitated relational affect, emotional regulation, comfort, and an interpersonal space in which to make sense of their bodily changes. However, the participants' narratives went beyond their perspectives about seeking lay referral and encompassed their perceptions of themselves with relation to other people's needs during the pandemic. This gave insight to the participants' relational schemas, their perceived concept of self and others in the context of the coping response of lay referral during the COVID-19 pandemic.

1.1 Positively views the self as typically actively engaging with, or increased lay referral with close others

The lower-level theme illustrates a sense of how participants felt increasingly able to, or continued to seek support from those within their close relationships. A sense of positive behavioural action arose in terms of engagement:

“Yes, the outbreak changed who I spoke to. During the pandemic, I spoke to more friends and family members than I would typically (normally I only speak my mum and best friends about any illness symptoms or bodily changes).”

(P51-S-SC1)

Lay referral during the COVID-19 pandemic also offered the experience of relational closeness:

“The outbreak of covid-19 has enabled me to become a lot closer to my family members, therefore I became a lot more comfortable around them and felt like I could talk to them about anything I was feeling.”

(P57-S-SC1)

1.2 Positively views others as responsive; regulatory lay referral and making sense

For the secure attachment style group, lay referral was viewed as an interpersonal experience in which their own needs were met. Through the participants' narratives, we can gain a sense of the perceptions in connection to others, and in relation to their perceptions of the lay referee:

“...I feel that I need more assurance now that something minor like a sore throat isn't COVID, as I'm anxious about having to isolate for two weeks. I always confide in my boyfriend about illness symptoms to get reassurance or comfort usually, especially if I'm in physical pain.”

(P32-S-SC1)

“In my opinion, this has made us closer as a family as we spent so much time together during lockdown, and now I’d probably feel more inclined to share with them whenever I felt unwell or had a headache.”

(P82-S-SC1)

For this group, an overall expression of responsiveness was captured, in which the participants felt that the lay referee possessed the capacity to respond adequately to support, comfort, and help them make sense of their experiences.

1.3 Positively views self as responsive to others’ needs in a pandemic; lay referral

The secure adult attachment style group’s narratives were not restricted to their own experience of lay referral but included how they perceived themselves in relation to others. It would appear that they not only viewed others as being responsive to their own needs, but they also viewed themselves as being reciprocally responsive to other people’s needs during the COVID-19 pandemic. This was often expressed by the participants when they wrote about supporting other people and how their interactions could or would have an impact on others:

“[I] reviewed government guidance for precautionary measures. Conversed with family and friends to offer support and create social circles where physical communication was not permitted (lockdown rules).”

(P5-S-SC1)

“I also spoke to my family regularly throughout my sickness... I also had to share information with my elderly neighbour who was shielding and relying on me to do his shopping and collect his prescriptions. This is something I would not have had to do previously as my health is not something, I consider necessary to share with him. In this instance, however... I had to inform him that I was sick and arrange alternative shopping arrangements as I had been working in a Covid-19 positive area.”

(P15-FA-SC1)

For the secure adult attachment style group, lay referral appeared to be a reciprocal coping process in which the participants were able to continue to gain support, whilst also providing support for others around them.

The Dismissing Adult Attachment Style Group

2 Typical Lay Referral Engagement and Relational Affect Disengagement

The main theme of *'typical lay referral engagement and relational affect disengagement'* illuminated how the participants in the dismissing adult attachment style group actively engaged with lay referral. This was similar to the secure adult attachment style group although held differences in the way in which the participants described their active engagement. For most of the participants in this group, the COVID-19 pandemic had not altered lay referral although, unlike the secure adult attachment style group, most of the participants did not refer to the interpersonal or potential emotional aspects of this process. For others in this group, the COVID-19 pandemic had changed who they spoke with, and the data indicates that there was a level of disengagement which stemmed from their negative perceptions of others, who may have worried, been scared, or judged them if they had engaged with lay referral. Here, disengagement reduced relational affect which may have been perceived and anticipated to increased negative emotion.

2.1 Positively views the self as actively engaging with lay referral

As for the secure adult attachment style group, the dismissing adult attachment style group each expressed an active engagement within lay referral, however, these participants focused on how lay referral had not changed during the COVID pandemic:

"It has not changed who I speak to. I would always ask family before healthcare professionals."

(P17-Dis-SC1)

"No, the outbreak of COVID-19 has not changed whom I spoke to about my well-being and illness. I have always cared about my health, so if anything happens to me, I have close people whom I can speak to - my mom, my dad, and my grandma."

COVID-19 situation did not change anything with my approach to my bodily changes and illness symptoms because I never hide when I do not feel well and try to find some help.”

(P90-Dis-SC1)

The narrative accounts of the participants in this attachment group projected a sense that the participants and their perception of themselves was continuing as normal, unadjusted in any way during the COVID-19 pandemic in regard to lay referral.

2.2 Decreased lay referral; negative view of others and relational affect

For others in the dismissing adult attachment style group, disengagement arose regarding lay referral. This was expressed through the participants' negative perceptions of other people, who were described as worried and/ or scared, or who may become more worried if the participants shared their experiences of bodily changes. In these accounts, the participants' concept of self and other are apparent, and how these relational schemas shape the anticipated responses in terms of relational affect during a pandemic:

“...I felt less likely to mention any bodily changes with my family or friends as I didn't want them to worry that I had got Corona.”

(P2-Dis-SC1)

“Yes COVID-19 has affected who I speak to as many people around me are worried and "scared". If I were to be ill which shared similar symptoms to COVID-19 I was unsure whether to tell anyone or speak about it due to "judgement".”

(P22-Dis-SC1)

Through the dismissing adult attachment style group's narrative, their perceptions of self, and other was evident. For some, the perception of themselves as actively engaging with lay referral arose; whilst for others disengagement was described based upon their negative perceptions of others' responses.

The Preoccupied Adult Attachment Style Group

3. Divergent Self and Other Perceptions; the Experience of Lay Referral

The main theme of *'divergent self and other perceptions; the experience of lay referral'* highlighted the between group differences in terms of adult attachment style and the participants' interpersonal experiences of lay referral. For example, both the secure adult attachment style and dismissing adult attachment style groups generally expressed a sense of active engagement within lay referral; and the dismissing adult attachment style group also discussed COVID-19 disengagement. In contrast, the narratives of participants within the preoccupied attachment style group indicated that they anxiously anticipated negative consequences in relation to how other people may perceive them if they talked about their bodily changes. Simultaneously, they perceived the lay referee as responsive, which aided their sense-making of bodily changes. The divergent complexity of the concept of self, and other, is apparent.

3.1 Negative anticipated consequences for the self; decreased, and avoidant lay referral

The below text narrative exemplifies how the perception of self influenced the process of lay referral during the COVID-19 pandemic. For some of the participants, there was a decrease of lay referral and what appeared to be an increase of avoidance, generated through the perception that sharing their experiences of bodily changes with others would result in negative relational and social consequences in relation to themselves:

"...I would not communicate with my friends about it as I would feel singled out and they may feel on edge around me."

(P23-Pre-SC1)

"With the current outbreak I've definitely withdrawn myself in relation to seeking help. Although I haven't experienced any COVID symptoms, I still chose to keep any changes pretty much to myself in fear that somebody would look at me differently or try and give themselves space from me, in fear that the outbreak is much more than it is."

(P44-Pre-SC1)

Here, the influence of people's perceptions of others is apparent, and how cognition shaped people's perceptions, and in turn their specific lay referral behaviours/coping responses.

3.2 Positively views others as responsive; affect-regulation, lay referral and making sense

The way in which the participants in the preoccupied adult attachment style group viewed the perceived consequences of lay referral in terms of the self and how they perceived others or the lay referee are different. Similar to the secure adult attachment style group but not the dismissing adult attachment style group, the preoccupied adult attachment style group perceived others as previously holding the capacity to respond in an adaptive way which regulated how they felt and supported them to make sense of their current experiences:

"I've spoken sometimes about these bodily signs - my palpitating heart or sweating - with my wife but she was always calming me down that it's stress and nothing else. Rationally, I know she must have been right. Apart from that it was quite alright."

(P1-Pre-SC1)

"The only person I managed to tell was my partner, as they saw me every day and would end up finding things different - so I really had no choice. They helped my irrational fears however, they didn't get weirded out if I got a stuffed nose or my old persistent cough came back (of which was very chesty, never dry)."

(P44-Pre-SC1)

Here, it is clear that those within the preoccupied adult attachment style group who engaged with lay referral experienced more than advice as to whether to go to the doctors or not. Lay referral was an interpersonal experience that offered relational affect-regulation and an opportunity to make sense of their bodily changes.

The Fearful-Avoidant Adult Attachment Style Group

4. *Decreased Fearful Avoidance and Hypervigilance of Lay Referral*

The main theme of '*decreased fearful avoidance and hypervigilance of lay referral*', further demonstrates the complexity of lay referral and how this process is experienced differently by different adult attachment style groups. For example, the fearful-avoidant group similarly discussed negative perceptions of the self in connection with lay referral (i.e. - didn't know how to describe their bodily changes, lack of importance in contrast to COVID, the consequences for others if symptoms are disclosed). They did this in a way, unlike the preoccupied adult attachment style group who perceived the lay referee as responsive, the fearful-avoidant group expressed fear concerning potential separation and social isolation if they were to engage in lay referral.

4.1 Lay referral; negative view of the interpersonal self

For the fearful-avoidant adult attachment style group, their negative perceptions of themselves appeared to have reduced their engagement with lay referral. For example, feelings of inadequacy, and that their experience was insignificant or obsolete compared to the pandemic was expressed:

"I was less likely to talk about any changes because I was worried about not knowing how to describe them..."

(P9-FA-SC1)

"I haven't been as open with family or healthcare professionals as my personal, smaller issues seemed obsolete compared to the pandemic..."

(48-FA-SC1)

Through the above, we are able to witness how people's perceptions of self potentially associated with attachment style shape lay referral.

4.2 Health related fear for others, hypervigilance, and help-seeking

As with the participants in the secure adult attachment style group, the fearful-avoidant group expressed an increase in potential lay referral although differences existed regarding the reasons why this had increased. For the fearful-avoidant group, there was a sense of hypervigilance and health-related fear and threat for others, family members, and friends during the COVID-19 pandemic. Sharing the experience of bodily changes appeared to act as a protective measure to reduce any health threats potentially faced by others:

“Normally if any concerns arose, I would go to my parents however, if I am concerned for any changes, I now seek help through online consultations with my GP to ensure nothing is possibly linked to corona due to my family being high risk.”

(P20-FA-SC1)

“The COVID-19 outbreak has certainly changed the way I have spoken about my bodily changes. I frequently get sore throats... I knew that some people had experienced a sore throat as a symptom of the virus, therefore I was anxious when I did get a sore throat even though I knew it was unrelated. My dad is quite high risk due to having severe asthma therefore I felt obliged to tell him when I had a sore throat just as a precaution, despite having no other symptoms.”

(P87-FA-SC1)

For some, lay referral offered a form of relational protection in the pandemic, a process that facilitated emotional regulation and relational affect.

4.3 Negative view of others, decreased lay referral, fear of isolation and separation

The decreased nature of lay referral for the fearful-avoidant group was similar to that expressed by the participants in the dismissing adult attachment style group. However, participants with a fearful-avoidant attachment style appeared to express a negative perception of others and fear in terms of isolation/ separation from others, if the symptoms they were experiencing were similar to the ones known to be indicative of COVID-19:

“I know many others aren’t as supportive as what were once viewed as common cold symptoms are now seen as symptoms of the virus which can now put a strain on relationships as it does make people distance from you physically and socially.”

(P87-FA-SC1)

“Recently, I suffered with a throat infection, this caused problems with my voice making me sound ill. I had no symptoms of covid. When out in public I would receive stares as people were concerned that I had COVID-19, this made me more self-conscious about who I spoke to. This is because I was worried that they would automatically assume that I had covid and this would mean I would have to isolate....”

(P71-FA-SC1)

Again, the complexity and influence of the concept of self and other is evident, how people’s perceptions of themselves and others shape their experiences and potentially influence the perceptions of social coping responses such as lay referral.

Professional Healthcare Help-seeking Behaviour in the Context of a World Pandemic

The final templates of the four adult attachment style groups are presented in this section. These illustrate how the outbreak of COVID-19 changed the participants’ help-seeking behaviour in relation to seeking professional healthcare advice (see the below final template. The abductive themes were generated through a template analysis which used a hard *priori* set of themes built upon adult attachment theory, and which focused on relational schemas, and the model of self and other (Bartholomew, 1990). The participants’ context is expressed within the COVID-19 pandemic, and provides insight to how the participants within one of four adult attachment styles sought and/ or did not gain access to healthcare services. The top-level main theme for the secure adult attachment style group was *‘active engagement and COVID related disengagement with healthcare services’*; the dismissing adult attachment style group *‘differing perspectives and access to healthcare services’*; the preoccupied adult attachment style group *‘differing perspectives and access to healthcare services’* and the fearful-avoidant adult attachment style group *‘decreased and avoidance of healthcare consultation’*.

Final Template of Professional Healthcare and Help-seeking Behaviour

The Secure Adult Attachment Style Group

1. Active engagement and COVID related disengagement with healthcare services

1.1 Positively views the self as actively accessing healthcare services

1.2 Altered negative perceptions of healthcare services, cautious and decreased access

The Dismissing Adult Attachment Style Group

2. Differing perspectives and access to healthcare services

2.1 Positively views the self as actively accessing healthcare services

2.2 Negative perceptions of healthcare services, cautious and decreased access

The Preoccupied Adult Attachment Style Group

3. Altered negative perceptions of healthcare services, cautious and decreased access

The Fearful- Avoidant Adult Attachment Style Group

4. Decreased and avoidance of healthcare consultation

4.1 Negative view of self as a healthcare service user

4.2 Negative view of healthcare services, and decreased access

Qualitative Results

The Secure Adult Attachment Style Group

1. Active engagement and COVID related disengagement with healthcare services

The main theme of ‘*active engagement and COVID related disengagement with healthcare services*’ was generated through the secure adult attachment style group data. Although some participants wrote about actively engaging with healthcare professionals, there was also an adjustment to their help-seeking and a sense of delay based upon the COVID-19 pandemic in terms of accessing services. For others, the context of pandemic altered how they perceived healthcare services which for some reduced engagement and/ or created a delay in help-seeking.

1.1 Positively views the self as actively adjusting and accessing healthcare services

The perceived engagement with healthcare services was active, although altered, and adjusted during the COVID-19 pandemic:

“During the pandemic, the role of the GP's changed due to social distancing regulations. They were only conducting phone consultations. Following a week of sickness and a negative Covid-19 test I remained unwell so my contact with the GP to request a sick note was by phone.”

(P15-S-SC1)

“Yes, it has changed. I have an underlying condition so worry about covid. I have contacted my GP more often than usual...”

(P94-S-SC1)

Here, for some, adjustment involved behavioural delay, whilst for others; increased proximity and consultation were sought, driven through worry.

1.2 Altered negative perceptions of healthcare services, cautious and decreased access

Altered perceptions arose in consequence of the COVID-19 pandemic in terms of healthcare services, or barriers with some of the participants expressing caution increased and engagement decreased:

“I also would be even less likely than normal to seek healthcare advice from a professional to avoid putting unnecessary stress on the system.”

(P32-S-SC1)

“Since the outbreak of covid 19 it’s really hard to get an appointment to see the GP. You ring them and the receptionist decides if you require a call from the doctor which I think it’s absolutely ridiculous considering they have no medical experience or training. It should be for the doctor to decide and it’s also not nice to have to explain to a receptionist why you are ringing, you like it to be kept confidential between yourself and your doctor.”

(P91-S-SC1)

For some, in the secure adult attachment style group, the pandemic altered, and decreased their engagement with healthcare services.

The Dismissing Adult Attachment Style Group

2. Active engagement and COVID related disengagement with healthcare services

The main theme within this attachment grouping held several similarities to the secure adult attachment style group and this will be further explored in the discussion section.

2.1 Positively views the self as actively accessing healthcare services

Active engagement with healthcare professionals and different services during the pandemic was seen:

“When lockdown restrictions eased, I contacted my GP for myself, after numerous conversations with family and friends about my own wellbeing. This was helpful as I had a telephone call, which led to an increase in medication.”

(P40-Dis-SC1)

“As I’m high risk from having a kidney transplant last year if I feel any changes, I do contact the hospital and talk to family or friends about it to get different opinions family and friends say to go to the doctors because of the transplant.”

(P50-Dis-SC1)

2.2 Negative perceptions of healthcare services, cautious and decreased access

Similar to the secure adult attachment style group there were negative perceptions of healthcare services within the dismissing adult attachment style grouping although the specific perceptions differed. For instance, the secure adult attachment style group’s narrative referred to system-level factors; whereas the dismissing adult attachment style group exhibited more of a focus upon interpersonal factors in terms of how healthcare services may have negatively judged or responded to them and how they perceived they might have been at risk by seeking healthcare advice:

“I’ve not bothered visiting my GP about it because I feel like it isn’t deemed ‘serious’ enough to visit a medical professional, especially during these COVID-19 times. I’m not normally one to complain about ailments unless it’s on-going or severe enough that home treatments don’t manage it well, which is especially true during the pandemic. Simply put, there’s bigger fish to fry.”

(P73-Dis-SC1)

“I have found that I am more reluctant to seek professional advice as I am worried about going into the GP surgery or hospital. The fear that I might come out of the surgery with a worse illness, such as COVID-19, is very prominent. I often will rather suffer with pains, than risk going.”

(P77-Dis-SC1)

The Preoccupied Adult Attachment Style Group

3. Altered negative perceptions of healthcare services, cautious and decreased access

Similarly, to the secure adult attachment style and dismissing adult attachment style group, the preoccupied adult attachment style group outlined how the pandemic had impacted upon their help-seeking behaviour, with a main theme of *‘altered negative perceptions of healthcare services, cautious and decreased access’* with selected quotes giving a sense of how COVID-19 has shaped these perceptions:

“...I fainted and had to be hospitalised and tested, and did not have Covid, but I feel I would have sought help from both my friends and from professionals sooner if it wasn't for the pandemic. Usually, I would be far more open and more willing to admit I'm ill and go to the doctors or accept help from the people I live with.”

(P17-Pre-SC1)

“Since the Covid outbreak going to the local GP has most definitely changed. With such strict measures, things like my back pain and strange unexplained tummy pain is pushed to the back burner. Therefore, since the outbreak of Covid I have not seen any professionals regarding my health, although I do need to.”

(P35-Pre-SC1)

Fearful-Avoidant Adult Attachment Style Group

4. Decreased and avoidance of healthcare consultation

The main theme of *‘decreased and avoidance of healthcare consultation’* discriminates the fearful-avoidant adult attachment grouping from the other groups. The main difference relates to how the fearful-avoidant group narratives outlined negative self-perceptions in terms of their help-seeking behaviour and their perceptions of healthcare services.

4.1 Negative view of self as a healthcare service user

For this fearful-avoidant group, the below gave insight into their perceptions of themselves which sometimes positioned others or other people's health as more important:

"COVID also means I'm less likely to speak to a healthcare professional, as they are focusing on COVID patients or suspected patients, and as well as not wishing to deduct time from such patients, I also am unwilling to visit a professional due to the risks posed by COVID."

(P37-FA-SC1)

"The outbreak of COVID-19 has changed who I speak to about illness symptoms and bodily changes, I have gained healthcare professional advice but have been hesitant about contacting doctors due to the belief that there are more important issues currently than my health."

(P79-FA-SC1)

The notion of deducting time from others or that there are more important issues than the participants' health in the pandemic is evident.

4.2 Negative view of healthcare services, and decreased access

As for the other groups, in the context of the pandemic, the fearful-avoidant group also expressed negative views of healthcare services. These related to changes in healthcare services, feeling uncomfortable and increased demands upon services:

"I usually have weekly therapy sessions with a mental health care team as an outpatient, as well as contact with a psychiatrist once a month, however, due to the outbreak of Covid in-person sessions were stopped and I didn't feel comfortable discussing personal issues and health problems over the phone or online, so I stopped communicating to professionals regarding any bodily changes."

(P41-FA-SC1)

“It has made me less inclined to speak to professionals as I feel like I am only experiencing minor illness symptoms (not Covid) and they are probably more busy right now.”

(P45-FA-SC1)

Similarly, between the groups, the participants' narratives made reference to the changes, challenges, altered and adjusted engagement or disengagement with healthcare professionals and services during the COVID-19 pandemic.

Discussion Section

The hypothesis for the quantitative component of the research was that personal factors (gender, life stage, attachment), situational stimuli, and previous illness experience will influence people's illness perceptions, lay referral, and help-seeking behaviour during the pandemic. Some evidence was found to support the hypothesis and the previous literature; with each method also producing differing knowledge (i.e.- statistical and narrative findings) which will be discussed below. Overall, the quantitative data provided a breadth of insight across the sample, however, to gain a more in-depth exploratory understanding, the qualitative data will be converged with the quantitative to offer an explanatory and theoretical perspective upon the results which was not found in the quantitative data. The rationale to converge the data is based upon the pluralist approach of this study which acknowledges that different methods produce different knowledge. This is important to recognise in the context of this theoretically orientated study, as both the quantitative and qualitative results provided different types of insight into the topic.

Personal Factors, Cognitive Illness Representations, and Coping Responses

Personal factors such as gender, life stage, and adult attachment style have previously been found to influence cognitive, emotional, behavioural, and coping responses when people experience a sense of disruption to their 'normative self' or somatic bodily experiences which activate cognitive prototypes (illness-related memory structures) or generate mental representations of illness/ health threats (Leventhal et al., 2016). Support of the previous literature is offered by the current findings. Although no significant difference was found in regards to illness

perceptions or help-seeking behaviour according to participant gender (female/ male), gender did significantly affect the social coping response of lay referral, with 94.5% of females engaging with lay referral (5.5% not) in comparison to 76.5% of men (with 23.5 not). This reinforced the results of the scoping review findings (see Chapter three) which demonstrated the influence of gender upon lay referral (Cornford & Cornford, 1999; Meininger, 1986).

In contrast to the previous literature, this study did not find significant effects of life stage upon illness perceptions, lay referral, and help-seeking behaviour. However, having a pre-existing health condition (PEHC stands for pre-existing health condition) (N=58) did affect these illness representations, and illness perceptions. All of the mean rank scores reported for the PEHC group were higher than the non-PEHC (N=36) in terms of the perceived consequence or effect of their bodily changes upon their life; the perceived timeline and duration of bodily changes; the identity of their bodily changes as illness symptoms/ illness concern; and their emotional representations activated through the experience of bodily changes. However, it is important to note, that although this between-group difference arose and the PEHC group reported higher mean ranks, these mean rank scores were moderate, not high (maximum of 100) (consequence= 54.22; timeline= 54.66; Identity= 55.22; illness concern= 52.47; emotional representation= 51.64) which may have influenced the participants' coping responses in terms of lay referral and help-seeking behaviour (Moss-Morris et al., 2002).

The activation of coping responses elicited through cognitive representations and illness perceptions in terms of bodily changes were indicated though a significant difference between those who engaged in lay referral and those who did not. This difference was found concerning the domain of perceived timeline; whereby those who engaged in lay referral had significantly higher mean rank score (47.84) than those who did not engage with lay referral (26.88). This suggested that these participants had a more chronic illness model (albeit still moderate). Despite this coping response activation, this study did not find that people's illness perceptions generated through bodily changes alone activated professional healthcare help-seeking behaviour. However, where a lay referent advised seeking healthcare advice, this did have a significant effect on actual help-seeking behaviour. This again supports previous literature which highlighted the influence that lay referral can have upon people seeking professional healthcare or medical advice (Freidson, 1970;

Zola, 1973; Cornford & Cornford, 1999; Smith & Ruston, 2013). However, another interesting point was that 69.8% did not gain HCP advice after engaging with lay referral when the lay referent did not suggest gaining HCP advice. These divergent results support the discussion in the scoping review (Chapter three) in reference to how lay referral does not always encourage professional healthcare advice.

The difference between people's reported coping responses when they experienced bodily changes in the pandemic could be further explored from an integrated perspective based upon CSM in terms of illness perceptions, interpersonal cognition, the relational self, and adult attachment theory. Firstly, there was a significant difference between adult attachment style groups with regards to emotional representation (secure $M = 5.12$; dismissing $M = 5.29$; preoccupied $M = 7.30$; fearful-avoidant $M = 7.00$) with a trend also seen in relation to perceived consequence. However, no significant difference between adult attachment style group /lay referral, and professional healthcare-seeking behaviour was found. One possible explanation in terms of this non-significant result could lay within the participants' perceived health threat in response to their bodily changes. For example, to gain more of an understanding of the complexity of the above cognitive, emotional, and behavioural processes, it is vital to explore the participants' perceived sense of health threat or if they perceived their bodily changes to be benign in connection with attachment style. No statistically significant difference in reference to the perceived threat was reported by the different attachment style groups. However, all groups reported only a low to moderate sense of health threat in relation to their symptoms with the mean rank scores suggesting a higher threat amongst the preoccupied adult attachment style and fearful-avoidant groups.

The high level of engagement with lay referral (91.2%) when people experienced bodily changes is to be expected in a novel way as part of this study. This expectation is based upon both the theoretical assumption that interpersonal experiences (self-with-other schemas) provide a filter that can guide attentional processes to relevant information which shapes the interpretation of ambiguous stimuli. Consequently, interpersonal processes act as an organising framework, which helps people make sense of their experiences. These assumptions relate to the traditional work in the field of social cognition in connection to relational schemas, although, there is an apparent lack of research in this domain following the early 2000s. The results do support the findings of the IPA study in Chapter four and

the wider body of work with regards to lay referral found as part of the scoping review (Chapter three). As part of the quantitative analysis no significant difference was found between the attachment style groups in relation to illness perceptions, lay referral, and help-seeking behaviour. However, findings regarding emotional representation indicated a mean difference between the secure adult attachment style group and the fearful-avoidant adult attachment style group. A trend was also found towards higher perceived consequences in the fearful-avoidant adult attachment style group than the secure adult attachment style group. Therefore, when thinking of both the quantitative and qualitative results concurrently as part of the design of this study, it is paramount to recognise that each of the data sets were considered to be equally weighted with neither type of data taking priority. This is important because each of the methods are underpinned by different assumptions (see the methods section) and produce different types of knowledge. For instance, as discussed in the introduction above, the different ways in which to explore attachment were considered in reference to self-report measures and the Adult Attachment Interview (Duschinsky, 2020). This highlights how the same topic can be examined through alternative methods each holding value, whilst producing alternative insights. In turn, although the quantitative analysis did not reveal any significant differences, the qualitative data enabled an opportunity to narratively explore how the different attachment style groups experienced the phenomena under investigation.

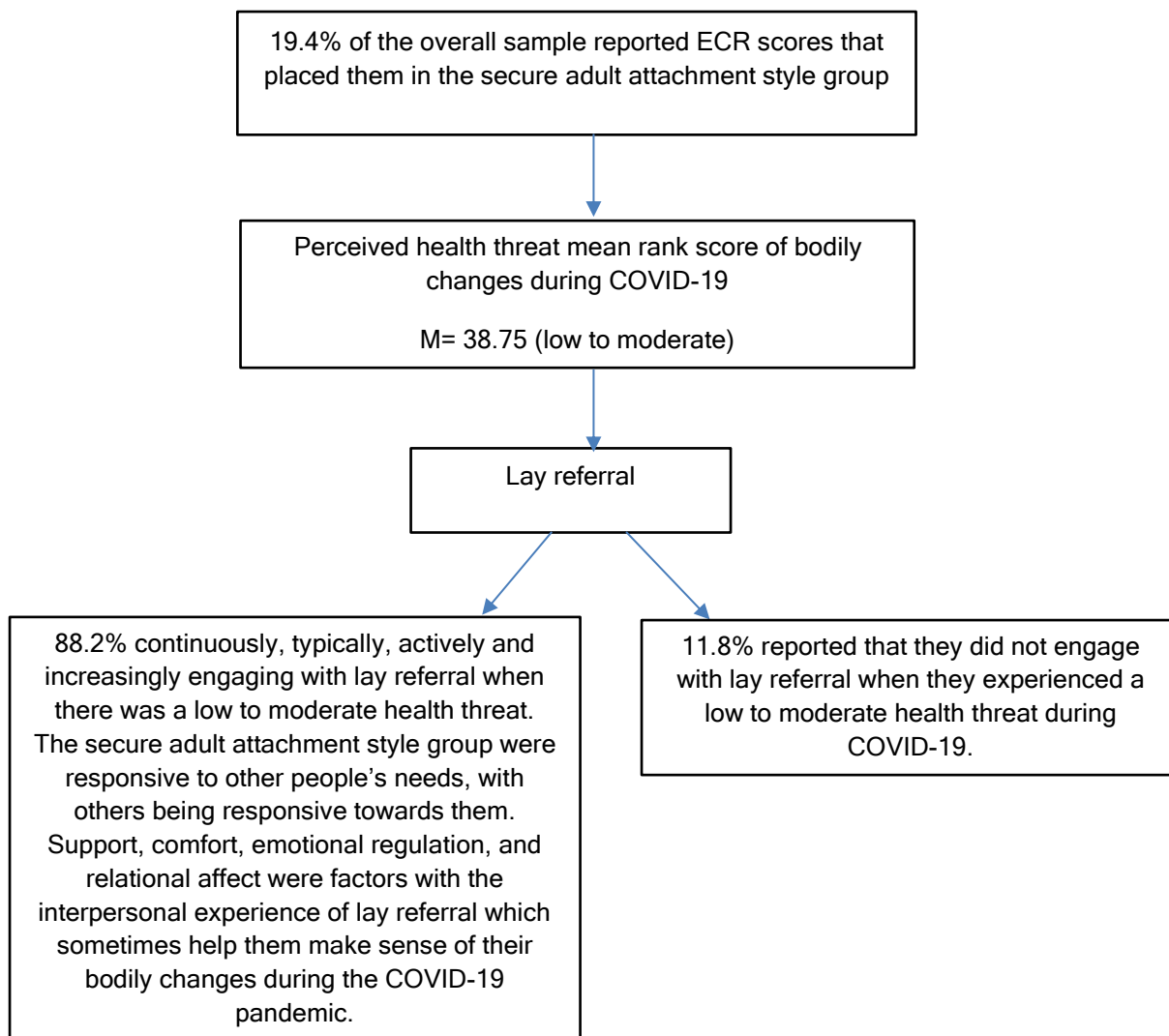
Attachment Theory, Relationally Informed Lay referral, and Help-seeking Behaviour

When conducting mixed and multi-method research, the triangulation of interpretation is paramount when considering the different types of results (Rugg, 2010). Here, through the methods triangulation (see Chapter two and the current methods sections) and the across method triangulation between the quantitative and qualitative data we will consider how to interpret both sets of data to answer the theoretically-driven research questions. The goal was to convergence the data, and narratively explore the experiential differences in lay referral and help-seeking behaviour between the different adult attachment style groups.

Lay Referral

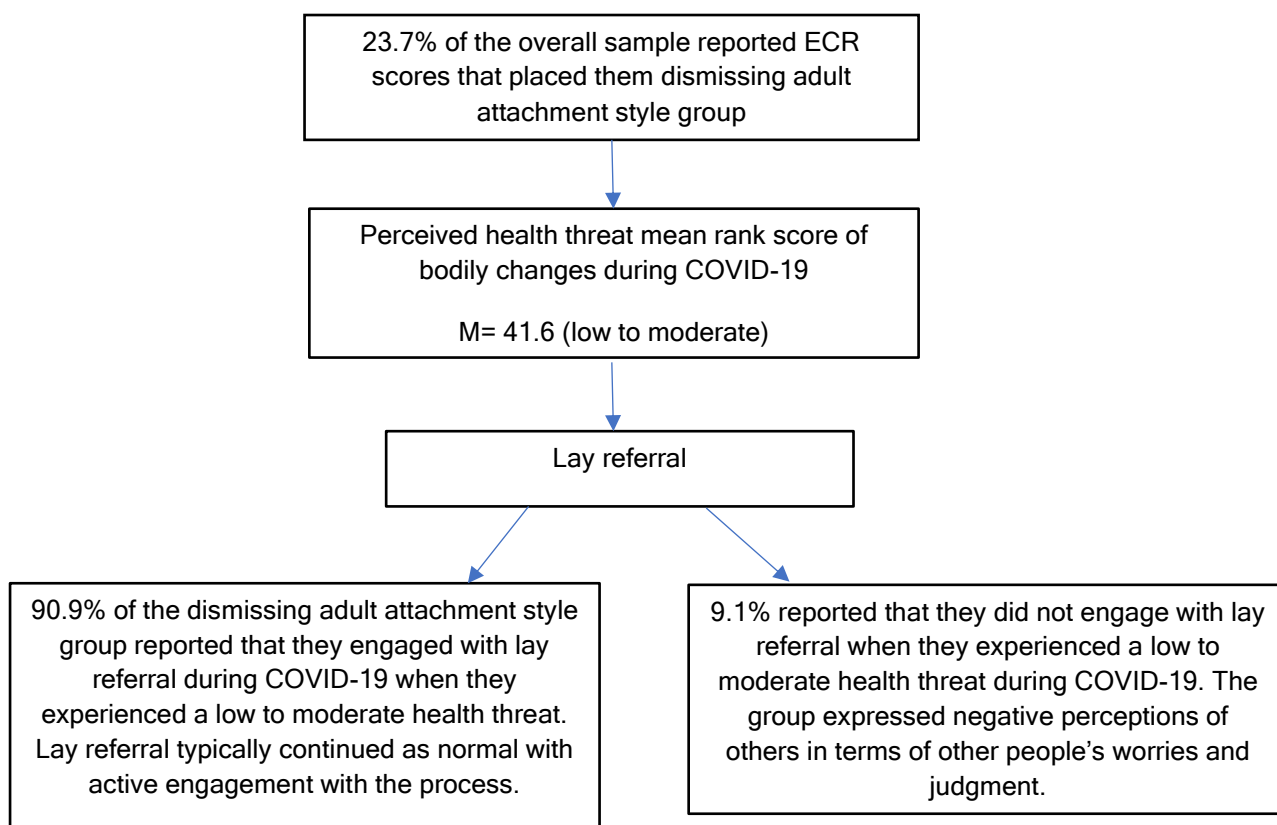
The Secure Adult Attachment Style Group

The abductive template analysis findings for the secure adult attachment style group generated the main theme of *‘responsive and reciprocal lay referral’* with regards to whom they spoke to about bodily changes/illness symptoms in the context of COVID-19. The lower-level themes included: *‘positively views the self as typically actively engaging with, or increased lay referral with close others’*; *‘positively views self as responsive to others needs in a pandemic; lay referral’*; and *‘positively views others as responsive; regulatory lay referral and making sense’*. Through the above, the reader can gain insight into how people’s attachment style likely shapes their relational schemas and their perception of lay referral. In accordance with Bartholomew (1990), the secure adult attachment results in these participants expressing a positive concept of self, and others, represented and perceived through the self as continuously, typically, actively and increasingly engaging with lay referral; the self as responsive to other people’s needs during the pandemic, and others being responsive or having capacity to respond adequately to offer support; comfort, and to help them make sense of their bodily changes whilst in a pandemic. These findings are consistent with adult attachment theory which advocates that those with a secure adult attachment express trust, feel comfortable with close interpersonal relations, express relationship satisfaction, and when under threat seek and maintain proximity with attachment figures (Baldwin, 2005; Hazan & Shaver, 1994). Theories of interpersonal cognition are also supported in connection to processing ambiguous bodily stimuli, and how lay referral is an interpersonal process influenced by relational schemas and/ or script like expectations of others (Duschinsky, 2021). For the secure adult attachment style group lay referral offered what seemed to be a comfortable relational space for intimacy, to alleviate distress, coping, adjustment, relational affect, emotional regulation, cognitive interpretation and increased perceived personal or social adjustment during the pandemic (Baldwin, 1992; 2005). Figure 5.10 below visually demonstrates a triangulation of the secure adult attachment style groups results.

Figure 5.10*A Triangulation of the Secure Adult Attachment Style Group Results***The Dismissing Adult Attachment Style Group**

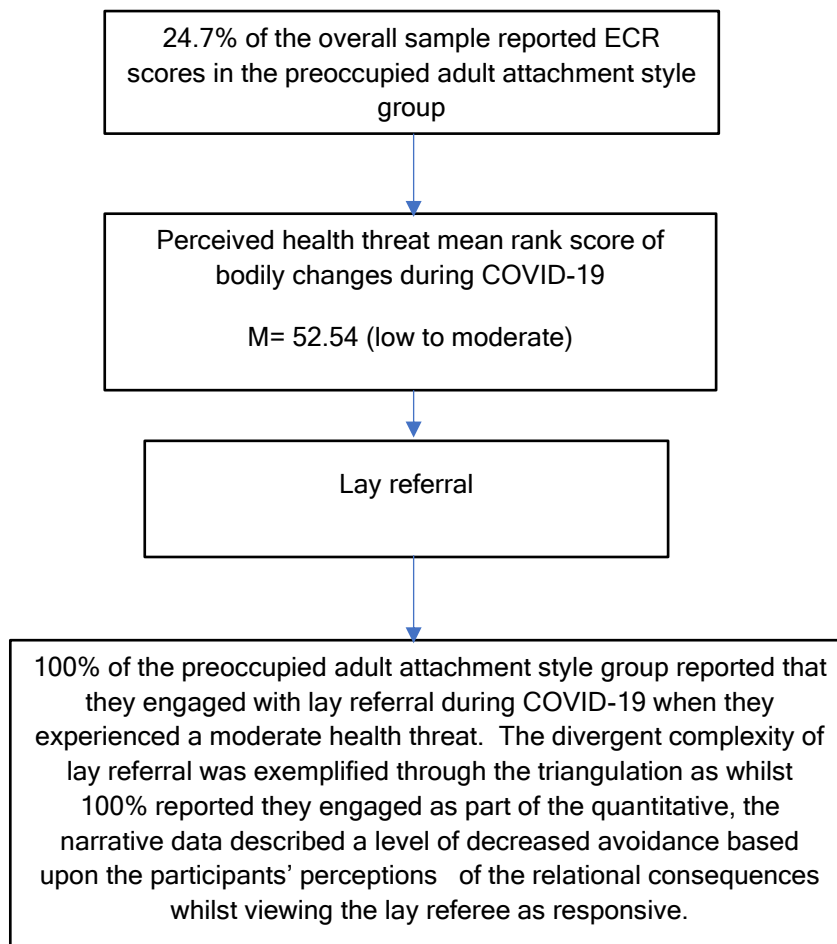
The main theme developed through the dismissing adult attachment style group data was '*typical lay referral engagement and relational affect disengagement*'; which encompassed the following lower-level themes '*positively views the self as actively engaging with lay referral*'; '*decreased lay referral; negative view of others and relational affect*'. The theoretical assumption that guided the *a priori* of themes were that the dismissing adult attachment style group may express a positive view of self, and a negative view of other (Bartholomew, 1990). Similar to

participants in the secure adult attachment style group, those with dismissing attachment styles expressed active engagement with lay referral, a positive view of themselves in terms of behavioural action, but the focus of the dismissing adult attachment style group narrative differed from the secure adult attachment style group here as the dismissing adult attachment style group focused upon the continuation of lay referral, as normal. The process of lay referral had not changed, with no reference to adjustments being made in the context of COVID-19. The negative perceptions of others, as part of lay referral were also evident with disengagement being motivated through their relational perceptions that other people were worried during COVID-19, and that if they were to share their experience of bodily changes, they may increase others' worries or other people may judge them. It appeared that the dismissing adult attachment style group's scripted expectations and anticipated responses of others, and potential relational affect decreased their perceived motivation with regards to lay referral. These conflicting perceptions which were often expressed at odds, supported the theoretical stance of this study; as people who report a dismissing adult attachment style often avoid closeness based upon their negative expectations, although maintain a sense of self-worth by denying the value of close relationships and may adopt attachment-deactivating strategies to try and deal with the threat alone (Bartholomew & Shaver, 1998; Mikulincer & Shaver, as cited in Baldwin, 2005). Therefore, through the participants' perceptions of themselves and others, we not only witness the interpersonal and relational aspect of lay referral but how the experience of lay referral differs both cognitively and emotionally across the different adult attachment style. Figure 5.11 visually presents a triangulation of this group results.

Figure 5.11*A Triangulation of the Dismissing Adult Attachment Style Group Results***The Preoccupied Adult Attachment Style Group**

Within this preoccupied grouping the main theme of *'divergent self and other perceptions; the experience of lay referral'* was generated with lower-level themes including: *'anticipated negative perceptions of others in relation to the self'*, *'decreased and avoidant lay referral'* and *'positively views others as responsive; affect-regulation, lay referral and making sense'*. The divergent perceptions in terms of self and other were evident, and how their perceptions were characterized by a negative self-concept but a positive concept of other (Bartholomew & Shaver, 1998; Bartholomew, 1990). Differences to the secure adult attachment style group, and dismissing adult attachment style group who expressed taking an active role in lay referral were seen. For the preoccupied adult attachment style group, their self-concept was negative and not positive as for the secure and dismissing adult

attachment style groups. This negative self-concept expressed itself through reported potentially scripted expectations and the anticipation that there would be negative relational consequences if they shared their experiences with others. These consequences included other people potentially feeling on edge around them, or that others would look at them differently and this often led to a decrease in or avoidance of lay referral. The expression of avoidance is interesting from an adult attachment theory perspective. According to the theory preoccupied individuals anxiously seek to gain acceptance and validation from others, with their belief being that if they gain validation, they can obtain safety (Bartholomew & Shaver, 1998; Bartholomew, 1990). Therefore, through an attachment informed perspective, it becomes apparent why the participants with a preoccupied adult attachment style expressed decreased engagement with lay referral. Given the context of COVID-19, and their dependence on affirmation from others to feel safe, they avoided health-related conversations which may create negative relational affect. The expectation of negative affect arose from the perception that other people may not respond to them in a way which would create interpersonal safety and adjustment during the pandemic. It is the preoccupied adult attachment style groups 'anticipated responses/ expectations' shaped through their negative concept of self and the experience of bodily changes during COVID-19 that created a variation of increased avoidance of lay referral. Although the preoccupied adult attachment style group differed in terms of active engagement with lay referral, they were similar to the secure adult attachment style group in expressing a positive view of other in terms of the lay referee. The presence of a negative self-concept coexisting with a positive concept of self highlights the interpersonal complexity of lay referral seen through a narrative and attachment theory lens. Some also expressed how the lay referee held the capacity to respond to their needs, which supported adaption and regulated how they felt, and also reduced their irrational fears. The process of lay referral appeared to present a process of additional attentional processing of bodily stimuli, and an interpretative process based upon interpersonal and/ or cognitively scripted knowledge (Baldwin, 1992; 2005; Duschinsky, 2021). The below figure 5.12 visually demonstrates a triangulation of this groups results.

Figure 5.12*A Triangulation of the Preoccupied Adult Attachment Style Group Results***The Fearful-Avoidant Adult Attachment Style Group**

The main theme for the fearful-avoidant adult attachment style group was *'decreased fearful avoidance and hypervigilance of lay referral'* and the lower levels themes developed were *'lay referral; negative view of the interpersonal self'*; *'negative view of others, decreased lay referral, fear of isolation and separation'* and *'health-related fear for others, hypervigilance, and help-seeking'*. The overall theme, as seen with the other attachment groups, highlighted the interpersonal and relational complexity of lay referral. Similar to the pre-occupied adult attachment style group, the fearful-avoidant adult attachment style group expressed a negative perception of themselves in connection to lay referral. These perceptions referred to

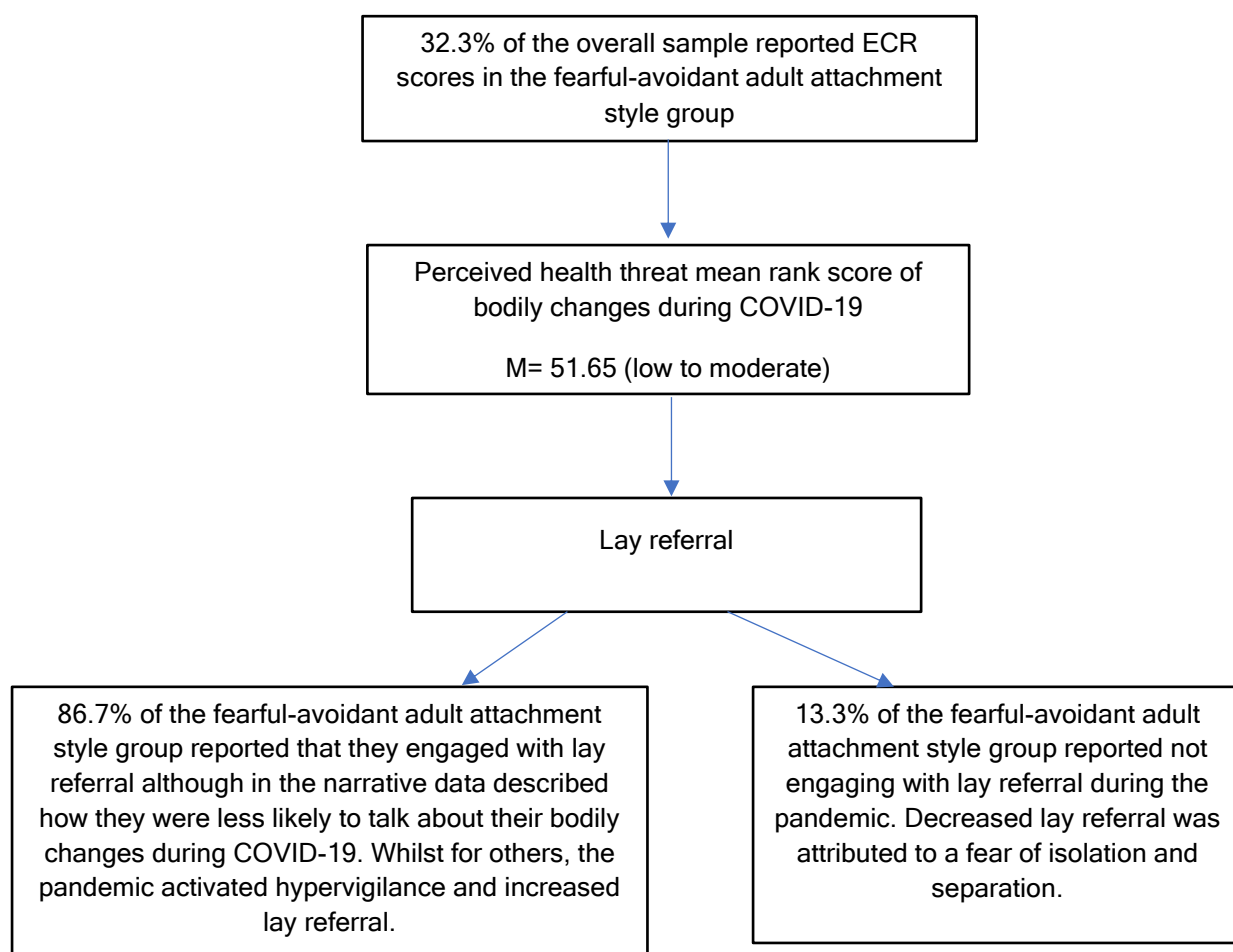
not knowing how to describe their bodily changes, feelings of inadequacy, and insignificance in the pandemic which led to a reduction in lay referral. This reduction of lay referral aligns with attachment theory (Mikulincer & Shaver, 2020), which suggests that fearful individuals are increasingly dependent upon other people's acceptance although due to their negative scripted anticipated expectations they avoid intimacy to avoid rejection (Bartholomew & Shaver, 1998). Avoidance was not the only emotional coping response witnessed when experiencing bodily changes during the pandemic as, similar to that seen within the secure adult attachment style group, some fearful-avoidant adult attachment style group participants reported an increase in lay referral. However, the experiential aspects of the fearful-avoidant group's narrative were different to the securely attached in that these participants expressed hypervigilance and health-related fear or fear for others. The increased use of lay referral appeared to offer a protective measure or precaution for others to reduce any health threats, and aid emotional regulation, and relational affect. From a mental representation of attachment security perspective, this hypervigilance in the pandemic could be explained through attachment insecurity in which the participants perceived lay referral as an essential coping response that created proximity when under perceived threat. In accordance with attachment theory, hyperactivated attachment systems involve increased vigilance to threat related cues and a reduced detection of the attachment figure's unavailability (Mikulincer & Shaver, as cited in Baldwin, 2005). The reduced detection of the attachment figure's unavailability is interesting when thinking about a concept of self and other, and offers insight to why the fearful-avoidant adult attachment style group may still seek proximity and express an increased engagement with lay referral when their scripted concept of other may typically be negative.

Similar to the dismissing group, the fearful-avoidant adult attachment style group also outlined reduced engagement with lay referral although again their narrative differed around the negative perceptions of others, and fear of isolation and separation from other people if they were found to be experiencing COVID-19. The decreased nature of lay referral for some and hypervigilance for others demonstrates the importance of individual differences. From an attachment perspective, if seeking proximity is unlikely to reduce distress (people perceived as unsupportive, increased self-consciousness) then people may adopt attachment-deactivating strategies, try to deal with the threat alone, and express self-reliant attitudes (Mikulincer & Shaver, as

cited in Baldwin, 2005). The below figure demonstrates the fearful-avoidant adult attachment style groups triangulation of results.

Figure 5.13

A Triangulation of the Fearful-Avoidant Adult Attachment Style Group Results

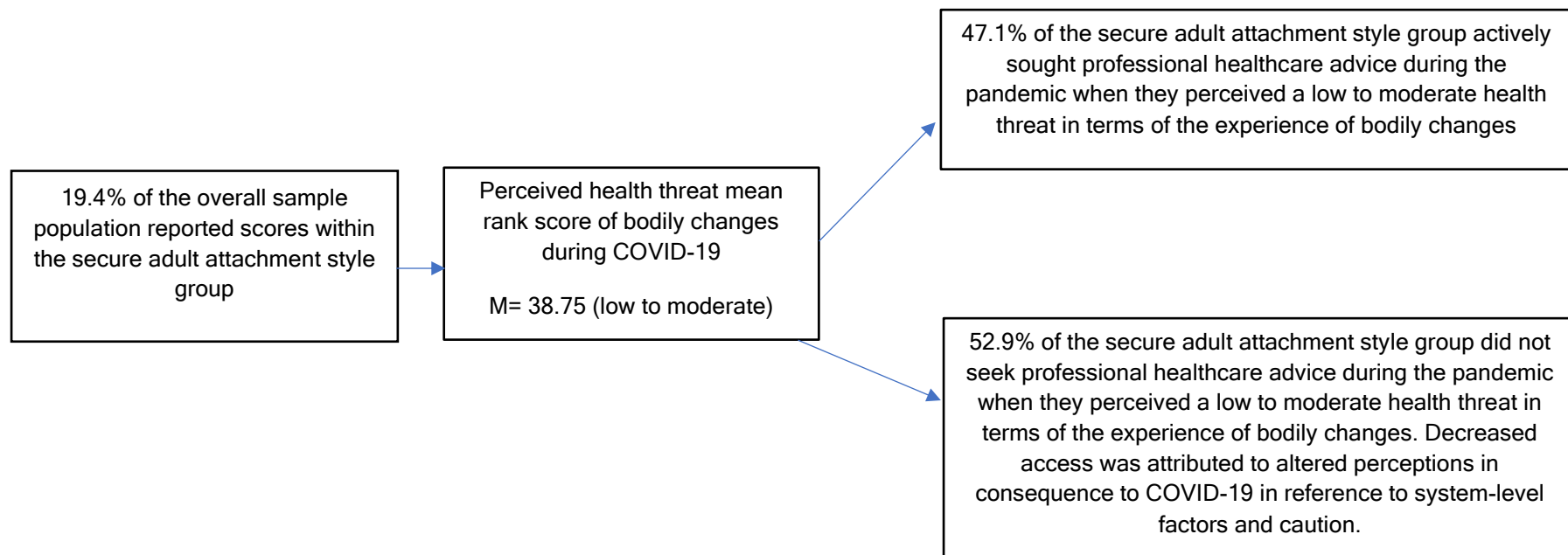


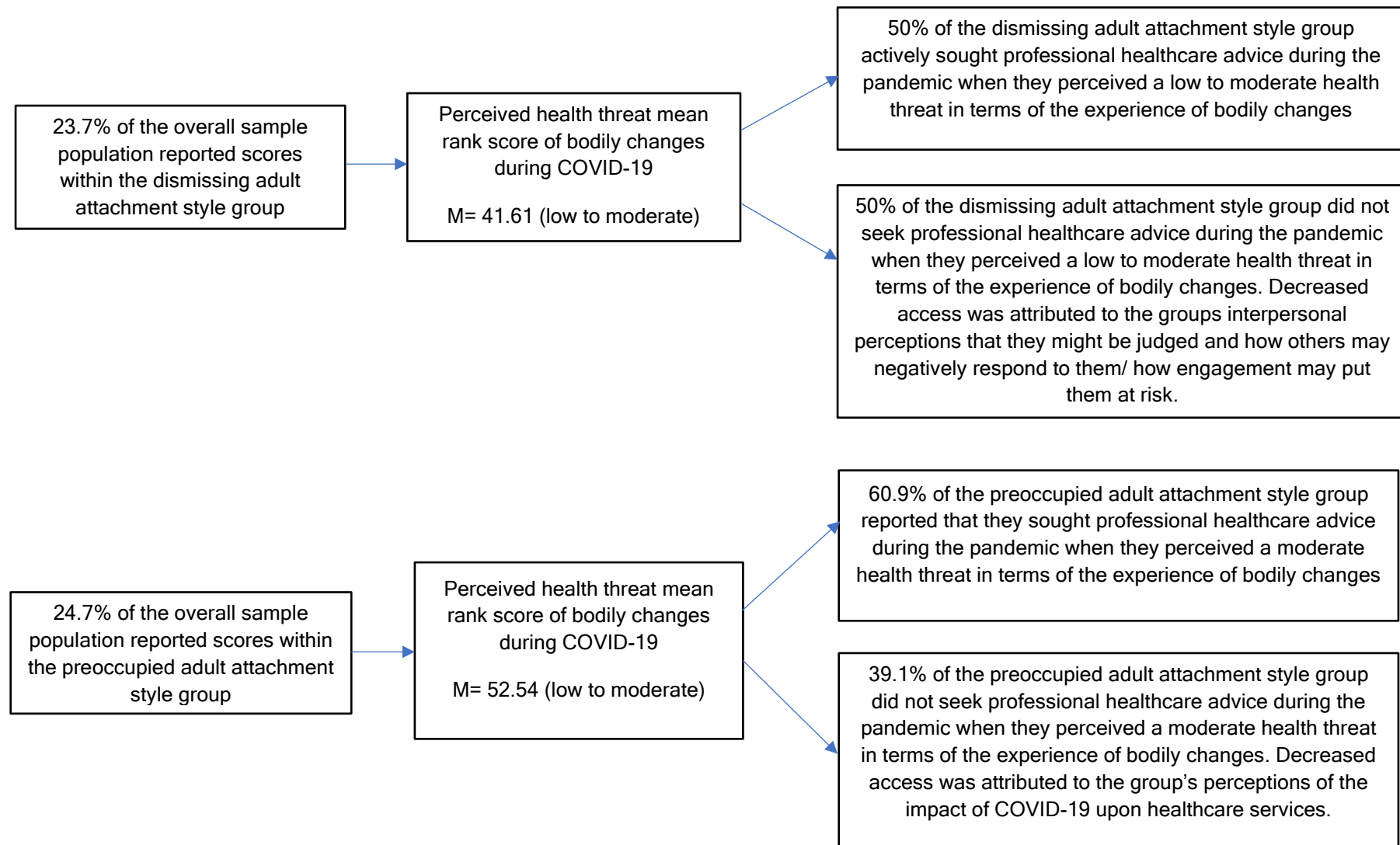
Professional Healthcare and Help-seeking Behaviour

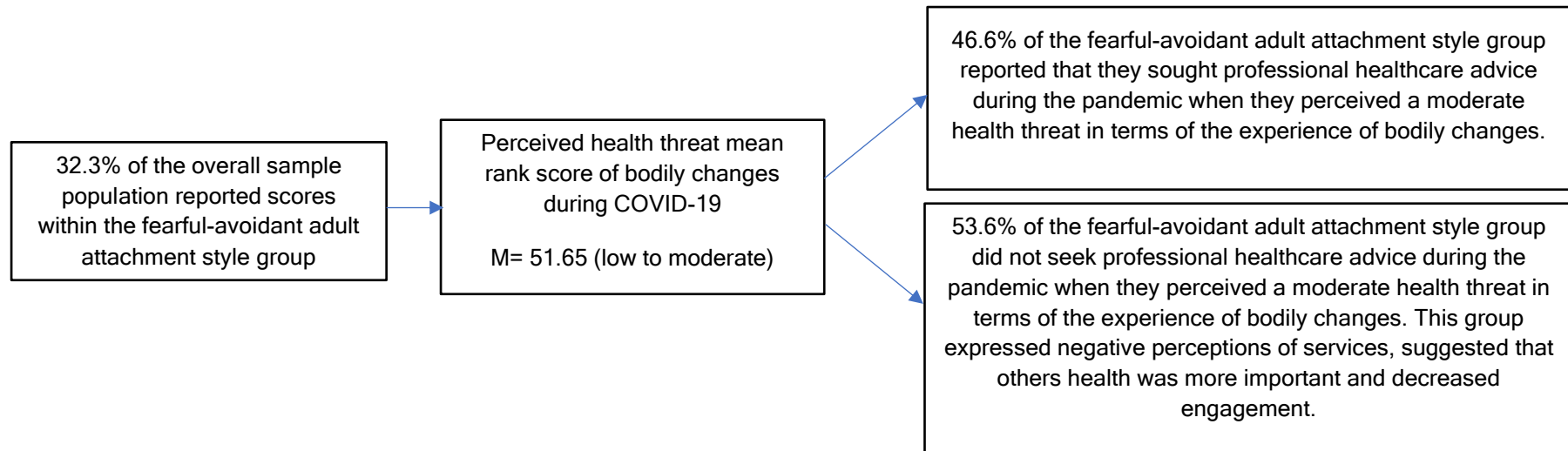
Figure 5.14 presents the different adult attachment style groups in the context of professional healthcare help-seeking behaviour during COVID-19. They have been presented together to demonstrate how a concept of self and other influenced the process but also to visually exemplify the contextual impact of the pandemic upon help-seeking perceptions and action.

Figure 5.14

A Triangulation of the Adult Attachment Styles and Help-Seeking Behaviour







The rationale for presenting the triangulation of the interpretation of results regarding the different adult attachment styles and professional healthcare seeking behaviour during the COVID-19 pandemic was to highlight the similarity of perceived health threat across the groups and the similarities in relation to engagement with healthcare services. Given the overall sample's low to moderate perceived sense of health threat, it is no surprise that there was no statistical difference between the groups. Scott (2013) outlined how people's perceptions of why they may discuss their symptoms with a healthcare professional are likely to be cognitively motivated. These cognitive motivations in accordance with Scott (2013) relate to the severity of people's illness perceptions in connection to the perceived consequence, timeline, personal control, treatment control, identity, illness concern, coherence, and emotional representations elicited through their bodily changes. The present study found a significant difference in regard to adult attachment style and the illness perceptions of emotional representation with a trend toward perceived consequence, and no significant difference between adult attachment and healthcare help-seeking. Given the low to moderate perceived health threat reported in response to bodily changes across adult attachment groups which may not have activated nor motivated the participants to gain advice; it is the qualitative data that gives us more insight into experiential and perceptual aspects of professional healthcare help-seeking during the pandemic. Overall, participants in each of the adult attachment style groups expressed either an altered perception of healthcare services, caution, or decreased engagement with professionals during COVID-19. For example, those in the secure adult attachment style group referred to system-level factors, services, and those in the dismissing adult attachment style group described negative interpersonal perceptions related to how others may respond to them in response to seeking help for bodily changes which may not be deemed 'serious' enough. In contrast, the fearful-avoidant adult attachment style group participants expressed negative views of themselves as service users (i.e. - the notion of deducting time from others, that other people's health is more important). Given that data collection for this study took place during COVID-19, the reduction of people's help-seeking and access to services is again of no surprise. This finding is supported by the systematic review of Moynihan et al. (2021) that explored the impact of the COVID-19 pandemic on the utilisation of healthcare services and found utilisation had decreased by about a third during the pandemic. One of the findings of the

systematic review which is highly relevant to this study's findings around perceived threat is that they found greater reductions in utilisation amongst people with less severe illness. This finding, therefore, offers some insight into the participants' wider social context and the impact of the pandemic upon help-seeking behaviour. Next the secure adult attachment style and dismissing adult attachment style groups are addressed who did describe seeking professional healthcare advice during COVID-19 drawing from the qualitative data.

Professional Healthcare and Help-seeking Behaviour; the Secure and Dismissing Adult Attachment Style Group

As part of the theoretically-driven abductive analysis, a similar lower-level theme was generated for the secure and dismissing adult attachment style groups based upon a positive concept of self (Bartholomew, 1990). This lower-level theme was *'positively views the self as actively accessing healthcare services'* and through this, it can be witnessed how a positive concept of self shaped how the participants expressed their behavioural engagement with healthcare services during COVID-19. For some in the secure adult attachment style group, their narrative related to an altered, adjustment and increased proximity (gaining advice) with healthcare services. This was also reflected in the dismissing adult attachment style group who sought healthcare advice, also based upon previous medical needs. From a theoretical perspective, this supports attachment theory and the notion that people seek or maintain proximity when under threat (Hazan & Shaver, 1994) and further supports other research. For example, Adams et al.'s (2018) systematic review of 34 studies (6 of the studies N= were over 400; 22 were between 100- 400; 6 had a sample less than N=100) identified a relationship between attachment style and treatment utilization (engagement, participation, completion) amongst those who experienced medical and mental health disorders. Most of these studies supported the association between attachment and treatment engagement, and attachment anxiety was found to be related to higher service engagement whilst attachment avoidance related to less (Adams et al., 2018). It could be suggested that in the context of the current study the experience of bodily changes and the COVID-19 pandemic appear to have elicited a sense of threat which for some of the adult attachment style groups activated help-seeking whilst for others it de-activated help-

seeking, decreased engagement, and increased avoidance. Bowlby (1969, as cited in Simpson and Rholes, 1998) argued that conditions of perceived threat activate attachment systems and that attachment differences are most evident under stressful situations. Here, through previous experience, people learn and develop scripts, affect-regulation, for instance, seeking support which is a characteristic of secure attachment. In contrast, if people have experienced previous rejection or insensitive responses, people learn not to seek support which represents itself through self-reliance which is a characteristic of avoidant related attachment (Simpson and Rholes, 1998). Therefore, through the qualitative data, we can gain insight into the complexity of help-seeking during a pandemic when people experience bodily changes.

In conclusion, this study which included a triangulation of interpretation demonstrated no quantitative group differences in terms of the personal and cognitive factors associated with adult attachment theory, lay referral, and professional healthcare help-seeking behaviour. However, effects of gender in relation to lay referral were found which supported previous literature (Chapter three/four; Cornford & Cornford, 1999; Meininger, 1986) as did a finding that having a pre-existing health condition influenced illness perceptions (Leventhal et al., 1992). It was through the convergence of data and the theoretically-driven abductive template analysis that the complexity of lay referral and help-seeking behaviour during the pandemic arose. Differences between how the adult attachment style groups expressed the process of lay referral and help-seeking were found. The role of relational representations, the concept of self and other was explored in the context of illness behaviour and the influence of the COVID-19 pandemic. Overall, there were experiential differences across the adult attachment group in terms of how they expressed, perceived, and experienced affect regulation, coping, and interpretative processes following the recognition of bodily changes. This highlighted the role of secondary attachment systems, which may be activated, hyperactivated, and/ or deactivated when people perceive a low to moderate health threat.

Chapter Six

General Discussion

Introduction

This General Discussion Chapter will revisit the overall aims of the thesis, and present a summary of the key findings from each Chapter. A synthesis of the key findings are then outlined, the contribution that these findings make to several different theories, policies, potential interventions, and future directions of research are discussed.

Revisiting the Aims of the Thesis

The overall aim of the thesis was to explore illness behaviour relating to the time frame between symptom recognition and whether people seek healthcare professional advice (or not) when they experience potentially cancerous bodily changes. The methodological orientation of each of the studies was developed to address some of the previous critique in the field as discussed in Chapter one. This enabled new insight with regards to the topic of symptom recognition, emotional coping responses, and lay referral. In consequence, this approach facilitated an exploration of what factors may influence the time frame, illness behaviour, supported the re-conceptualisation of lay referral based upon the participants' data, and an integration of psychological theory.

An Overall Discussion of the Key Findings

Factors that Influence the Perceptual Recognition and Interpretation of Bodily Changes and/ or Illness Symptoms

Potentially, many different factors shape the process between symptom recognition and attendance at primary care. The findings of the empirical studies are discussed below.

The Role of Disruption. The results of the IPA study (Chapter four) gave narrative insight into the multifaceted nature of symptom recognition when bodily changes could not be labelled medically or cognitively identified as illness symptoms. Bodily changes were not salient enough to cognitively represent typically known illness symptoms. Therefore, perceptual recognition existed across an experiential continuum of ambiguous, fleeting physical sensory experiences. These bodily changes were often noticed through a range of non-persistent disruptions to daily

activity, a spectrum of emotion due to the ambiguity of their experiences, and/or through changes in physical appearance. These challenges in terms of recognising, identifying, and labelling their bodily changes as illness symptoms, were apparent across the participants' accounts which is consistent with the Common Sense Model of Self-Regulation (CSM) (Leventhal et al., 2016).

The perceptual recognition of bodily changes and illness representations was further explored during the COVID-19 pandemic in Chapter five. The COVID-19 pandemic was incorporated within the study design as a contextual factor. The inclusion criteria were that participants had experienced self-reported bodily changes or physical illness symptoms in the last 3 months (amongst other criteria). Illness perceptions were captured through The Brief Illness Perception Questionnaire (BIPQ) (Broadbent et al. 2006). The overall sample mean rank scores for each of the adult attachment style groups was explored in relation to perceived health threat in response to bodily changes in the context of the COVID-19 pandemic. The secure group mean presented with the lowest perceived threat (for more information about the different attachment style groups see Chapter five). The fearful-avoidant and preoccupied group demonstrated an increased perceived threat although overall expressed a moderate health threat in connection to the experience of bodily changes. This quantitatively demonstrated the low to moderate health threat the participants self-reported in connection to the experience of bodily changes that may or may not be cancerous during the COVID-19 pandemic period. Furthermore, the only trend found in terms of illness perceptions and adult attachment was in connection to the perceived consequence, and emotional representation, although the trend was interpreted with caution. Given the participants' low to moderate perceived health threat and moderate mean scores across the subdomains of the BIPQ, the perception of bodily changes, illness representations, and emotional representations may not have been sufficiently activated in the current sample. In consequence, the results of Chapter five supported the findings of Chapter four which infers that bodily changes are not always salient enough to cognitively represent typically known illness symptoms or increased/ severe health threats (i.e. cancer). It is therefore proposed that people draw upon other cognitive, emotional, and relational factors to increase cognitive processes of ambiguous bodily stimuli. These results are consistent with the integrated theories of interpersonal cognition which is discussed in more depth as part of Chapter four (Baldwin, 1992; 2005) and

highlights the important role of interpersonal cognition in the context of the time frame.

The Role of Pre-Existing Health Conditions. The results of the mixed and multi-method study presented in Chapter five also exemplified how the perception of bodily changes in terms of illness perceptions can be shaped through people's experience of pre-existing health condition(s). For example, the results demonstrated a significant difference between those who reported the experience of a pre-existing health condition(s) (PEHC) compared to those who did not. This highlighted the role of previous illness experience and how the experience of a pre-existing health condition(s) shaped the participants' cognitive illness representations, and illness perceptions. For instance, all of the mean rank scores reported for the PEHC group were higher than the non-PEHC in terms of the perceived consequence of bodily changes upon their life; the perceived timeline and duration of bodily changes; the identity of their bodily changes as illness symptoms/ illness concern; and their emotional representations activated through the experience of bodily changes. However, it is important to note, that although the PEHC group reported higher mean ranks, these mean ranks scores were moderate, not high (see Chapter five). Thus, highlighting that moderately perceived or activated illness representations elicited through the experience of bodily changes during the COVID-19 pandemic, suggested that people may draw on other factors to make sense of their bodily stimuli (as described in the narrative data). These findings are explored in more detail as part of Chapter five and support the previous literature in regards to how previous illness experiences can influence illness representations of illness threats in relation to illness perceptions associated with BIPQ domains (Leventhal et al., 2016).

The Role of Relational Schemas, Affect and Self-Evaluation. In addition to the influence of previous or existing health conditions established in Chapter five, Chapter four revealed that perceptual awareness of bodily stimuli increased through the potential activation of interpersonal cognitive knowledge and script like expectations (Sakellaropoulo et al., 2006; Duschinsky, 2021). This was demonstrated through the expression of a lack of relatedness to the participants' perceived 'normative self' (i.e., as a perfectionist) or 'relational self' within their interpersonal space (e.g., at a performance level at work or recognised through

expected communication norms with others) which increased the experience of negative affect. The participants drew upon learnt patterns of relatedness in terms of themselves (self-comparison not social comparison) in order to process, and self-evaluate their ambiguous, fleeting experiences. The interpersonal aspect of the participants' experiences demonstrates the complexity of recognition when bodily changes are ambiguous and not salient enough to cognitively activate prototypes (illness-related memory structures). Moreover, it was suggested that the participants cognitively drew upon their learnt patterns of relatedness, and socially acquired information to process ambiguous bodily stimuli. This demonstrated the role of how self-schemas and self-with-other schemas facilitate additional cognitive/ attentional processing through people's interpersonal experiences which guides their attention, shapes perception, and alternatively provides default information to help people make sense of ambiguous stimuli (Baldwin, 2005; Sakellaropoulou et al., 2006).

In terms of the existing literature (i.e., Hagger et al., 2017) interpersonally acquired attentional processing in connection to the perception of non-salient bodily stimuli cannot be fully explained by CSM in terms of the personal characteristics (lifestyle activity, previous illness, and treatment). Instead, the findings of the IPA study, suggest an integration of theories associated with interpersonal cognition which could be embedded in CSM to account for the role of relational schemas (self-schemas and self-with-other) in terms of cognitively oriented self-evaluation grounded in interpersonal cognitive representations. This integration was discussed in Chapters four and five in relation to the previous literature which situated theories of interpersonal cognition within the topic of depression, anxiety, and low self-esteem within several theoretical publications (Baldwin, 1994; Sakellaropoulou, 2006).

The Role of Ambiguous Interpretation, Affect-Regulatory Responses, and Relationship-centred Anxiety. Findings of the IPA study demonstrated that the interpretation of bodily changes was often cognitively informed in terms of the potential labels associated with the bodily changes, but also emotionally mediated through the meaning associated with the different appraisals (i.e., menopause vs. anxiety and stress). These findings indicated that the participants faced difficulties around clearly labelling, cognitively organising and evaluating non-salient stimuli and bodily changes. This was echoed in the results of the mixed and multi-method study, where participants self-reported a perceived low to moderate sense of health threat.

The challenges around cognitively evaluating non-salient stimuli in terms of interpretation were explored in depth as part of the IPA study. Here, affect-regulatory responses were explored (dismissal and/ or interpretative avoidance) as a possible response to processing difficulties of ambiguous bodily stimuli. Consequently, these regulatory responses support the emotional coping responses outlined as part of the CSM in terms of cognitive and emotional avoidance coping strategies in the context of illness (Hagger et al., 2017).

However, what the CSM cannot explain is how the interpersonal uncertainty experienced by the participants in the study presented in Chapter four appeared to influence affect-regulation (fear, panic, anxiety, sadness, and depression) in response to the interpretation(s) of bodily changes. With this in mind, adult attachment theory was proposed as a way of understanding the participants' responses when they experienced an ambiguous health threat and potential relational threat that increased negative affect (Duschinsky, 2020; Mikulincer & Shaver, 2020). Adult attachment was drawn upon in the empirical studies, specifically from an affect-regulation perspective in terms of the concept of relationship-centred anxiety (Feeney, as cited in Simpson & Rholes, 1998). For example, relationship-centred anxiety could have been inferred through the expression of death related anxiety which appeared to create psychological anticipation of physical and emotional relational separation from the participants' loved ones. A second experiential and relational aspect of affect-regulation, for some in the IPA study, was when they perceived others as not believing their experience of bodily changes, rejected the health threat, and/or where there was a lack of responsiveness when they spoke with close others. These findings again arguably from an attachment perspective, activated a sense of emotional, experiential and relational separation from other people and possibly increased their experience of relationship-centred anxiety. Relationship-anxiety, the experience of threat and potential separation (i.e., perceptual/ projected emotional, psychological and physical) during the COVID-19 pandemic was also found as part of the multi and mixed methods study. This arose in connection to lay referral and will be discussed in more detail later in this Chapter.

The key findings of this thesis exemplify the relevance of interpersonal/ relational factors and attachment systems in connection to symptom recognition, coping and help-seeking. This demonstrating how these processes do not exist in a

vacuum but instead all interact and influence each other across the time frame between symptom recognition and help-seeking. However, it is acknowledged that these interacting factors may represent themselves, manifest or shape different aspects of the time frame in different ways depending upon the perceived sense of threat (i.e., health threat, relational threat, individual appraised threat based upon attachment schemas during lay referral or a combination of all). In consequence, the role of affect-regulatory responses and relationship-anxiety in the context of ambiguous bodily stimuli interpretation highlighted the importance of building upon the existing health psychology literature to incorporate relational cognitive representations that reflect the interconnected nature between the individual and the social world, from a life span perspective. This life span relational perspective has been found to be important and not only to shape self-schemas, self-with-other schemas, potential attachment styles, relational-affect, and affect-regulation but also illness behaviour.

The Role of Ambiguous Interpretation, a Positive Concept of Other and the Lay Referee. The narrative data collection as part of the studies presented in Chapters four and five was paramount in terms of exploring and gaining a more in-depth understanding of illness perceptions and interpretative processes outside of those captured by the BIPQ. An important aspect of this data is how it further exemplifies how the interpretative processes are interconnected with lay referral but not in the traditional sense (see Chapter five). For instance, the findings indicated that those participants in the secure adult attachment style group expressed that one aspect (amongst others discussed below) of lay referral was that it provided an interpersonal experience in which they made sense of their bodily changes with others (i.e., a sore throat not COVID-19 symptoms). Lay referral as part of the sense making process was also echoed as part of the result for the preoccupied adult attachment style group who also expressed relational responsiveness in terms of the interpretation of their bodily stimuli during this time of threat. For the preoccupied adult attachment style group, lay referral offered an interpersonal space for relational affect-regulation and to make sense of their bodily changes when they were not salient enough to cognitively represent typically known illness symptoms. Similarly, the comparison between the secure and preoccupied adult attachment style groups in connection to their perception of how lay referral facilitates making sense of their

experiences was not the same as the other adult attachment style groups. This highlighted the important contribution that a person's attachment orientation, scripted expectations, and/ or a 'positive concept of other' has as each of these groups perceived the lay referee as responsive and capable of responding to their needs when making sense or interpreting their bodily experiences. Therefore, the role of activated attachment systems could arguably influence symptom recognition beyond that of social comparison, with relational interpretative processing of ambiguous stimuli shaped also through attachment orientation (i.e., shaping if additional cognitive processing is sought from others) (Baldwin, 2005). The role of the lay referee building upon theories of interpersonal cognition and attachment could also be considered in terms of relational regulation theory, which outlines how people regulate their emotions, thinking, and behaviour through these types of conversation as opposed to interpersonal or relational conversations that are specifically about coping itself (Lakey & Orehek, 2011). This indicates that it is not necessarily only the content of these interactions which offer regulatory value but the relational process itself activates affect-regulation (proximity with close others during lay referral when script expectations indicate safety/ adjustment).

Factors that Influence Emotional and Social Situated Coping Responses in the Context of Lay Referral

The Role of Lifespan Experiences

The IPA study (Chapter four) demonstrated the powerful influence that previous familial experiences and lay referral have across the lifespan. The results illuminate how the participants reflected upon a sense of relational difficulty, a lack of responsiveness, and challenge grounded within other family members' experiences of illness across the lifespan (i.e.- parental experiences of anorexia in childhood). It was through these sometimes longstanding unattuned, inconsistent, rejecting, and/ or unpredictable family relational dynamics, that the participants generally reflected upon their family norms/ how they learnt to communicate, think and feel. The role of life span experiences was discussed in connection to Andersen and Chen (2002) who argued that the relational self is developed through people's previous knowledge which provides a foundation for people to make sense of their present

experiences and how past relational experiences are embodied which form an understanding of themselves in connection to others and shapes their mental representations. The influence of previous experience was exemplified through the articulation of comparable experiences across childhood which was reflected in their adult experiences of lay referral (i.e., how they avoided health conversations/ lay referral in a learnt attempt to manage their close relationships or because of an anticipated lack of sympathy/ empathy). This offered an opportunity to develop the concept of lay referral through a relational lens and to incorporate the concept of the relational self. This proposed conceptual integration is not only important in terms of our contemporary understanding of lay referral but also to the concept of the relational self in the context of illness behaviour, as it appeared that this area has not undergone development for some time.

The previous negative experience of lay referral was also found to be important in connection to how these experiences potentially shaped their cognitive expectations, negative emotional responses and current engagement with lay referral. The experience of negative emotion elicited through negative relational experiences consequently affected if or whether people engaged or avoided lay referral in response to ambiguous bodily changes. This can be demonstrated in Chapter four when people expressed that sharing health related information in adulthood was not always helpful and in fact was maladaptive when close others were not responsive, rejected, or dismissed the participant's health related experiences during lay referral. This often led to the expression of increased negative affect and, for some, discussions around relational avoidance. Here, attachment theory was drawn upon as a way to understand how people retrospectively make sense of seeking relational proximity (or not) through script like expectations during a health threat and lay referral (Duschinsky, 2020; 2021). The findings of Chapters four and five support the suggestion that when people perceive attachment figures or close others as insensitive (based upon their scripted mental representations) this can result in insecurity, which in combination with appraised threats can elicit further increased negative affect as the relational space is appraised as unsafe (Mikulincer & Shaver, as cited in Baldwin, 2005). Another important aspect of the empirical findings is that when people appraise lay referral or seeking proximity with others as not likely to ease distress, people may encounter secondary attachment strategies such as attachment- deactivation in which they

distance (i.e.- avoid relational closeness or their need of others) themselves from others to cope. These deactivating strategies may include not engaging with others when under threat, and not acknowledging their vulnerability (Mikulincer & Shaver, 2020). This highlights the significant role of '*relational appraisal*' as part of lay referral which is considered to be a novel application of the concept in connection to illness behaviour (see figure 6.2). Therefore, it is apparent how important life span experiences are in conjunction with the other relational factors outlined in this Chapter which in accordance with the review has not been previously explored in the context of lay referral.

The Role of Social Context; the COVID-19 Pandemic. The mixed and multi-method study (Chapter five) took a pluralist approach to encompass contextual factors such as the COVID-19 pandemic. This was considered to be very important given the potential perceived/ actual environmental health threat. The findings of the mixed and multi-method study demonstrated a high level of engagement with lay referral (91.2% of the overall sample) during the pandemic in response to the participants' bodily changes. This high level of engagement also identified the role of people's interpersonal experiences (their cognitive self-with-other schemas) that provide a filter, guide attentional processes, and act as a cognitive organising framework, which helps people make sense of ambiguous stimuli or bodily changes (Baldwin 2005) (see Chapters four and five for a more in-depth discussion).

The role of contextual, situational, and environmental threats was also an important aspect of this study which could account for the high level of engagement with lay referral. For example, Eder et al. (2021) conducted a cross-national (Austria, Spain, Poland, and the Czech Republic) seven week longitudinal study that examined the predications of fear and perceived health during COVID-19. The weekly surveys gathered information from 533 participants about a range of variables (i.e. perceived vulnerability to the disease (PVD), economic, psychological, and social factors). The findings demonstrated that 23% of the variance could predict fear of the virus when predictive factors included PVD, and worry about food supplies. Other predictive factors of perceived health included physical exercise, attachment anxiety, and age although the authors noted that the effect sizes were smaller in terms of these predictors. Eder et al. (2021) as part of the conclusion highlighted the importance of psychological micro level factors when considering fear

and perceived health as the macro level factors tested as part of the study (i.e., environmental factors related to the spread of COVID-19 and government social restrictions) did not influence nor contribute to the predictive results. This draws attention to the importance of individual level factors and illustrates how the context in which the mixed and multi-methods study (Chapter five) took place may have also influenced the participants' experiences (i.e., environmentally activated attachment systems) of lay referral.

The impact of the COVID-19 pandemic has been recognised in the literature as a traumatic stressor when considering people's reactions. For example, early on in the COVID-19 pandemic, Bridgland et al. (2020) highlighted how there is an increasing volume of research that has identified traumatic stress symptoms in the context of a continuing global stressor. Investigating this further, Bridgland et al. (2020) conducted an online study across five countries with a sample of 1,040 participants that examined if events people had been directly exposed to during the COVID-19 pandemic, anticipated events, and/ or indirect events through the media, had influenced traumatic stress symptoms. Data was gathered through the Posttraumatic Stress Disorder Checklist-5 that captured pre-, peri-, and post-traumatic responses, general emotions, well-being, psychosocial functioning, depression, anxiety, and stress symptoms. The results indicated that people experienced PTSD-like symptoms in regards to events that had not taken place if they had direct experiences of COVID-19 or indirect exposure through the media etc. It was found that those who have experienced the 'worst' exposure or anticipated this level of emotional impact predicted PTSD symptoms. Bridgland et al., (2020) concluded that the COVID-19 pandemic could be considered a traumatic stressor in which people may experience PTSD-like reactions which could increase the experience of depression and anxiety, etc. Therefore, given this emerging literature in terms of the contextual and environmental impact of the pandemic, it is recognised that the COVID-19 pandemic may have activated certain regulatory systems. Lay referral was explored again in Chapter five in reference to adult attachment in the context of the COVID-19 pandemic as discussed below.

The Role of Relational Schemas, Attachment, a Concept of Self and Other. The findings of the mixed and multi-methods study not only supported but theoretically built upon the IPA study which contextualised lay referral in terms of the

different adult attachment styles and Bartholomew's (1990) theoretical four-category diagram of the model of self and others. The results of the abductive data analysis exemplified the experiential differences of the sample and revealed how the different adult attachment style groups perceived, responded, and engaged (or disengaged) with lay referral during the COVID-19 pandemic. A range of experiential similarities and differences in regards to the experience of lay referral itself were found and are outlined below in terms of how potential secondary attachment systems were activated, deactivated, or hyperactivated. The activation, deactivation, and hyperactivation of attachment systems during the experience of bodily changes, supported the existing literature during a time of health threat (such as COVID-19) (i.e. Mikulincer & Shaver, as cited in Baldwin, 2005; Mikulincer & Shaver, 2009; Mikulincer & Shaver, 2020) and gives an interesting perspective upon how these attachment systems may function in a pandemic.

Activated Attachment Systems; COVID-19. The participants in the secure group (positive concept of self and other) (Bartholomew, 1990) expressed a positive sense of self represented and perceived through the self as continuously, typically, actively, and increasingly engaging with lay referral. The self was expressed as responsive to other people's needs during the pandemic, and others being responsive or adequately able to offer support and comfort. For the participants in the secure group, lay referral offered what seemed to be relational space for intimacy, to alleviate distress, coping, adjustment, relational-affect, emotional regulation, increased cognitive processing with regards to interpretation, and increased perceived adjustment during the COVID-19 pandemic (Baldwin, 1992; 2005; Mikulincer & Shaver, 2020). Whereas, for the preoccupied group (negative concept of self and positive of other) (Bartholomew, 1990) although divergent perceptions arose with some actively engaging and others potentially deactivating or avoiding lay referral (as discussed below); some expressed a positive view of the lay referee and how they held the capacity to respond to their needs, supported and regulated how they felt during the COVID-19 pandemic. These findings are consistent with adult attachment theory in terms of the participants in the secure group expressing relational closeness, relationship satisfaction, seeking proximity with attachment figures during a health threat (Baldwin, 2005; Hazan & Shaver, 1994; Mikulincer & Shaver, 2020). Another theory which could be integrated when thinking

of the positive role close others have, is relational regulation theory which again highlights how the process acts as a regulatory factor as opposed to the conversations themselves (Lakey & Orehek, 2011).

Hyperactivated Attachment Systems; COVID-19. Hypervigilance during the COVID-19 pandemic was also found as part of the mixed and multi-methods study. For some in the fearful-avoidant group, increased engagement with lay referral, a sense of hypervigilance, health-related fear, and health related fear for others was seen. The hyperactivated process of lay referral appeared to offer a relational regulatory protective measure to reduce any health threats faced by others that could be transmitted by the participants. This reduced the projected anticipation of relational separation through ill health, with proximity regulating their emotions and COVID-19 related fear. These results which are discussed in much more detail in Chapter five supported the previous literature in relation to how hyperactivated attachment systems involve increased vigilance to threat related cues, a reduced detection of the attachment figure's unavailability, and how hyperactivated systems reflect attempts to gain support and/ or love whilst feeling uncertain if the other person will be able to provide this (Mikulincer & Shaver, as cited in Baldwin, 2005; Mikulincer & Shaver, 2020). These findings, however, not only supported previous research but Steele's (2020) more recent paper that theoretically considers the role of fear in connection to the COVID-19 pandemic from an Attachment Theory perspective. The potential traumatic impact of the pandemic through an attachment lens was discussed in Chapter five and how the pandemic may increase fear of the future, fear of the loss, the prospect of loss of love itself, and separation.

Attachment- Deactivating Strategies; COVID-19. The mixed and multi-method study not only illuminated levels of active engagement or hypervigilance but also the experiential aspects of decreased and/or avoidance of lay referral during the COVID-19 pandemic. For instance, decreased engagement with lay referral arose for the dismissing group (positive concept of self, negative view of other) (Bartholomew, 1990). Here, disengagement could have been generated through the group perceptions about other people's experience of negative emotions (i.e., worry, anxiety, sadness, or fear) and how the lay referee's negative emotions may increase if they were to engage with lay referral or that they may be judged for sharing their

experiences. Avoidance of lay referral was also found within the pre-occupied group (negative concept of self and positive of other) (Bartholomew, 1990) based upon perceptions that there would be negative self-consequences if they shared their experiences during COVID-19. This was further echoed by the fearful-avoidant group (negative concept of self and other) (Bartholomew, 1990) in which divergent experiences were expressed, although those that related to avoidance of lay referral made reference to negative views of themselves as part of the process and fear of isolation and separation. These potential attachment strategies and the deactivation of attachment systems in reference to avoidance was discussed in Chapters four and five. These findings support previous literature and offer an expansion of application in the context of symptom recognition and lay referral (i.e., Mikulincer & Shaver, as cited in Baldwin, 2005; Mikulincer & Shaver, 2020). This is important because there has been very little development in the area and especially with regards to illness behaviour.

The Role of Gender and Lay Referral. The process of lay referral and the role of adult attachment, and relational schemas were further examined in the mixed and multi-methods study conducted during the COVID-19 pandemic, as presented in Chapter five. The quantitative results of the survey found a significant gender difference between females and males with regards to engagement with lay referral during the pandemic with 94.5% of females and 76.5% of men engaging with lay referral. This supports the previous literature found as part of the scoping review (Chapter three) and is discussed in detail in terms of gender differences, sex differences, and comparisons (i.e., Cornford & Cornford, 1999; Meininger, 1986). The previous literature offers differing explanatory insights as to why this may be the case. However, there appears to be a lack of research underpinned by gender related theory which may give more in-depth explanatory value in connection to lay referral.

Factors that Influence Professional Healthcare and Help-Seeking Behaviour

The Role of Past Healthcare Experiences

The IPA study gave rich insight into the powerful role of previous help-seeking experiences in the context of professional healthcare services and the potential activation of relational prototypes/ schemas/ mental representations beyond that of close others. Some participants expressed having previously experienced challenging interpersonal interactions with healthcare professionals, and they alluded to a sense of relational difficulty and experiential unresponsiveness in the patient-doctor relationship. The participants frequently articulated how their individual needs (physical, emotional, and/ or relational) went unmet, which indicated that their help-seeking behaviour became maladaptive and reinforced their negative beliefs, negative relational perceptions, the concept of others, and heightened lack of trust in regards to gaining healthcare advice.

The complexity of previously and actively seeking healthcare advice was demonstrated. The participants expressed a focus upon the appraised interpersonal aspects of help-seeking and relational communication. At times (amongst other factors) this related to the simultaneous need for contact with healthcare professionals (potential hyperactivated proximity seeking) and a sense of increased anxiety (relationship-centred anxiety/ negative perceptions) when healthcare professionals were appraised as discouraging or unresponsive in terms of a diagnosis etc. Similarly, for some, discourse related to avoidant help-seeking behaviours grounded within previous negative experiences and on occasion related to fear. This indicated that those who '*relationally appraised*' seeking healthcare as very unhelpful, ineffective, anxiety-provoking, or something to be fearful of, affect-regulated through physical/ emotional distancing and avoidant behaviours (attachment-deactivating strategies) (Mikulincer & Shaver, as cited in Baldwin, 2005; Mikulincer & Shaver, 2009). This deactivation strategy, in consequence, removed the potential risk of feeling rejected (unheard by professionals or their health needs being left unresolved based on previous experience), negative affect, and also removed any insensitive interpersonal interactions during consultation. The concept of wider '*relational appraisals*' which influence help-seeking behaviour is a concept that has been part of this thesis and reflects processes considered to be linked to lay

referral although also relates to wider relationships. See Chapter four, for more details and the proposed conceptualisation of how these relational, cognitive, and affect-regulation processes interact (figure 4.5, *the proposed role of attachment, the relational self, and professional healthcare seeking*).

The role of previous experience in the context of seeking professional healthcare advice when people experience bodily changes that may or may not be cancerous illness symptoms may also be shaped through the relational self, wider self-with-other schemas, and/ or relational representations that relate to prototypes influenced through life span experiences. Mikulincer and Shaver (2020) outline how attachment theory could provide a theoretical base for the application of attachment theory in people's relationships beyond significant others such as relationships with those in education and healthcare services. For example, Mikulincer and Shaver (2020) indicated that the broader application of attachment theory could be drawn upon to explain psychological functioning grounded in the following three points:

1. Distress and the experience of threat can activate attachment systems, and working models of self and others which influence people's thinking, motivations and behavioural responses.
2. People's responses are influenced through the quality of interpersonal interactions with the person who may fulfil the attachment figure role during the period of threat. These other people are generally targeted in terms of proximity when they experience threat or maybe context-specific, in that they offer a safe space and/or secure base.
3. Sensitive and responsive interactions create a specific relational context to create alternative relational interactions which could build cycles of attachment security, increasing more positive outcomes through these relational interactions themselves.

Mikulincer and Shaver (2020) suggest that the above principle can be applied to a range of domains in which people experience threat or feel distressed when there is a person who can offer a safe space/ secure base in which the person is responsive and sensitive, facilitating adjustment. The other person may or may not be a close or

significant other, or have an emotional relationship with them, but could also be a person that has a formal role such as a manager, teacher, or therapist, etc.

Moreover, Mikulincer and Shaver (2020) claim that those under threat and who receive responsiveness and support can counteract any projected insecurity and create meaningful changes in terms of psychological functioning. This highlights the important role of other more distant people as outlined above such as healthcare professionals, teachers, and therapists, etc. This potential important role of more distant people from an attachment theory perspective relates to interpersonal responsiveness and how previous difficult interactions may activate secondary attachment systems that lead to deactivation and avoidance of help-seeking.

Mikulincer and Shaver (2020) highlight how there is a lack of research in this domain and the role of attachment in the context of healthcare. Here it is also important to note Mikulincer and Shaver (2020) have been referred to throughout this thesis as during the literature search it would appear that they are one of few groups addressing this area.

The Role of a Positive Concept of Self and Activated Help-seeking; COVID-19. The findings of the mixed and multi-method study demonstrated how the participants' concept of self shaped their own perceptions of their personal engagement or access to services during the COVID-19 pandemic. For example, some of the participants within the secure adult attachment style group expressed actively engaging with healthcare professionals due to worry; whilst others described an adaption or adjustment which created a delay during the COVID-19 pandemic. This was also reflected in the dismissing adult attachment style group who sought healthcare advice based upon factors such as previous medical needs. From a theoretical perspective, this again supports attachment theory and the notion that people seek or maintain proximity when under threat (Hazan & Shaver, 1994; Mikulincer & Shaver 2020) and gives insight to how help-seeking could be understood through Bartholomew's (1990) theoretical four-category diagram of the model of self and others/ scripted expectations (Duschinsky, 2021).

The Role of a Negative Concept of Self; COVID-19. The powerful role of a negative concept of self in the context of seeking professional healthcare advice in response to bodily changes during COVID-19 was exemplified through the fearful-

avoidant attachment style group (Chapter five). The results gave insight into the participants' perceptions of themselves as service users and how these perceptions shaped their narrative in terms of help-seeking. For instance, some of the participants positioned the health of others as more important, how they would be deducting time from others, and how there are more important issues than their own health during the COVID-19 pandemic. These findings are again consistent with Bartholomew's (1990) and gave an expanded perspective of the four-category diagram in terms of professional healthcare help-seeking behaviour.

The Role of a Negative Concept of Healthcare Service and the De-activation of Help-seeking; COVID-19. The design of the mixed and multi-method study incorporated contextual factors such as the COVID-19 pandemic. This was an important aspect of the study and one that demonstrated the impact of the pandemic upon the participants' perceptions of healthcare services. This can be exemplified as each of the adult attachment style groups expressed either an altered pandemic induced perception of healthcare services, caution with regard to help-seeking, or decreased engagement with healthcare professionals. The participants in the secure group outlined challenges in reference to services, the dismissing group described negative interpersonal expectations of how others may respond to them if they gained professional input, and the fearful-avoidant group expressed negative perceptions as service users as well as negative perceptions of healthcare service providers. These results show the significance of contextual factors in connection with peoples' perceptions and illuminated how people's '*relational appraisal*' of healthcare services during the pandemic also elicited potential wider deactivating strategies (Mikulincer & Shaver, as cited in Baldwin, 2005; Mikulincer & Shaver, 2009; Mikulincer & Shaver 2020).

Theoretical Contribution to the Time Frame

The findings of this thesis contribute to several theoretical areas in health psychology such as The Model of Pathways to Treatment (MPT) (Scott et al., 2013) in terms of the application of CSM, interpersonal cognition, the relational self, relational schemas, relationship-centred anxiety, adult attachment theory, relational appraisals, and the proposed relational conceptualisation of lay referral. These

differing theoretical integrations and conceptualisations are discussed throughout this Chapter and the overall thesis. Chapters four and five in turn hold relevance to the expansion of the MPT in connection to the ‘appraisal’ and ‘help-seeking’ intervals. The studies designed as part of this thesis subsequently enabled an opportunity to propose several areas of theoretical development to build upon the existing theory in the field. Through the inductive IPA study, factors that were important to the participants were illuminated and then translated into variables for exploration in the mixed and multi-methods study. In turn, the pluralistic approach facilitated a theoretically oriented study.

The Recognition of Bodily Changes, Emotional Coping, Lay Referral and Help-seeking

Symptom Recognition

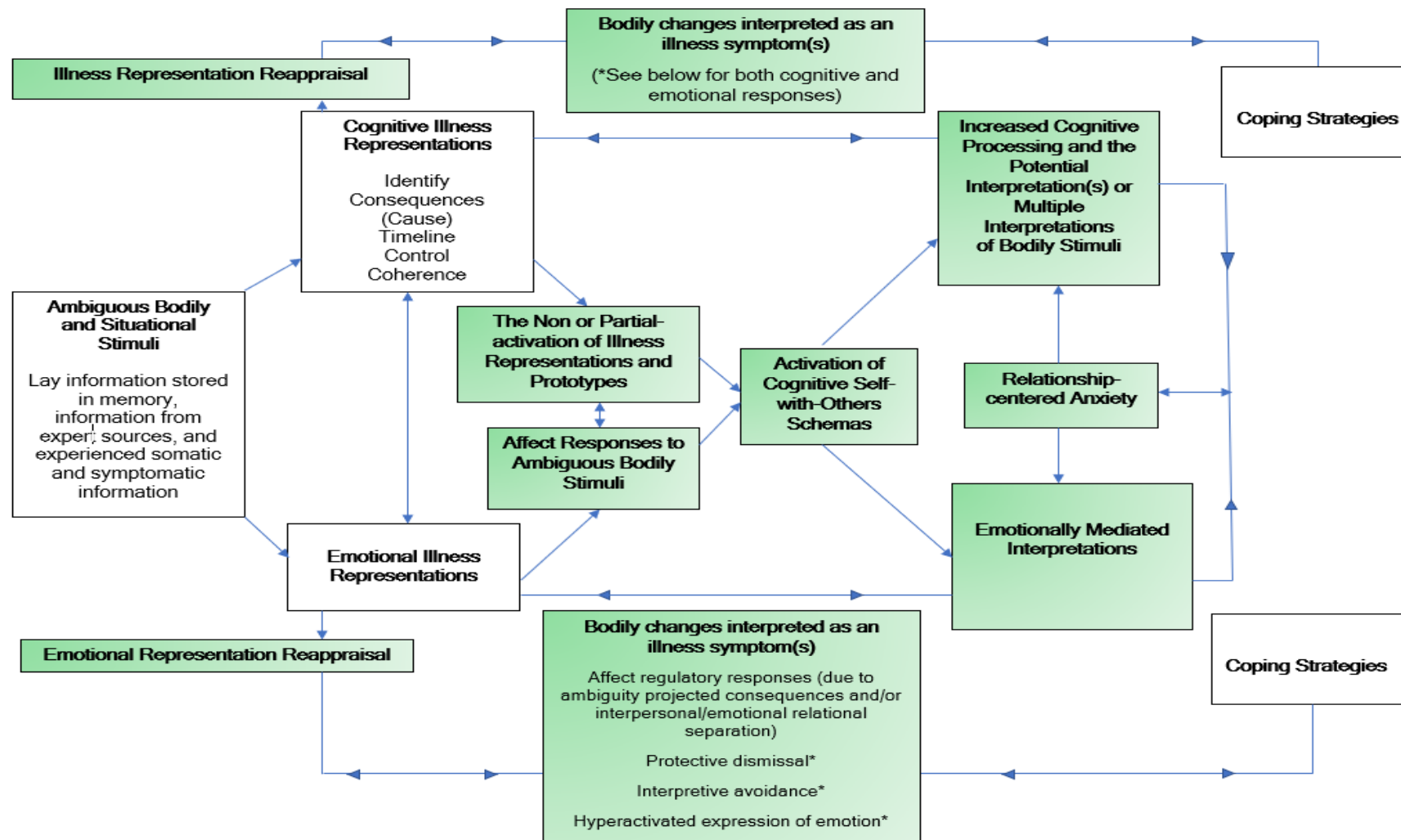
The overall findings of the thesis indicate that during the ‘appraisal interval’ (Scott et al., 2013) people drew upon cognitively oriented relational, interpersonal representations (schemas) and affect-regulatory responses when processing and interpreting ambiguous stimuli. The role of these factors in terms of symptom recognition should be acknowledged as a contributing component to what has been described (Scott et al., 2013) as ‘patient factors’ in connection to the ‘events’ and ‘processes’ that may occur between the detection of bodily change(s) and the perceived reasons (or not) to discuss symptoms with healthcare professionals. The qualitative findings offer an alternative experiential and more in-depth perspective upon the ‘appraisal interval’ in response to bodily changes, which may or may not be cancerous illness symptoms. The novel contribution to the Model of Pathways to Treatment (Scott et al., 2013) moved beyond that of the more social cognitive theoretical concepts previously described in the literature. For example, Scott et al., (2013) theoretically proposed concepts related to (although not exclusive to) the normalization of bodily stimuli which may not exceed a certain threshold of interference, which explained how these complex differing levels of interference cognitively contribute to the awareness of and perception of bodily changes. However, the results of the thesis indicated that ambiguous bodily stimuli are not necessarily normalized adaptively to enable continued functioning, but may

alternatively activate interpersonal representations, self-schemas/ self-with-other schemas, affect-regulatory responses, relationship anxiety, and lay referral as a process in which to increase cognitive processing of stimuli. As far as the researcher is aware, these relational concepts have not previously been applied to the process of physical bodily symptom recognition.

The IPA study, therefore, demonstrated how interpretation(s) of bodily signs were not only related to the bodily stimuli itself exceeding certain thresholds and thus activating illness prototypes/ mental representations, but also arose from ambiguous non-salient bodily changes. The interpretation(s) of bodily changes did not appear to be based upon automatic processing arising from cognitive heuristics, rather interpretation appeared to be emotionally mediated. This offered insight into how automatic processes associated with heuristics may be mediated through differing meanings linked to different or multiple simultaneous appraisals and interpretations (i.e. - menopause vs. anxiety and stress) (Chapter four). These results highlighted the role of affect-regulatory responses in connection to heuristics and interpretation, and how the emotional response to the meaning associated with a certain symptom(s) or illness(es) may lead to emotionally elicited avoidance and dismissal of interpretation. The contribution of these findings involves bringing together several different theoretical conceptualizations that offer a new integrative explanation. This involves the integration of relational uncertainty and negative affect-regulation (fear, panic, anxiety, sadness, and depression) when people experience bodily changes that may elicit multiple interpretations of illness symptoms. In consequence, the below (figure 6.1 which is a reproduction of the model in Chapter four) offers an adapted version of the CSM model. This relates to symptom recognition, the non-activation (or partial) of illness representation or multiple interpretations, emotional representations, the role of affect, self-with-other schemas, emotionally mediated interpretation, and relationship-centred anxiety in response non-salient bodily stimuli. The below encompasses a dynamic process when illness representations are not activated (or partially activated) but are cognitively and emotionally reappraised as part of a feedback loop, following the activation of relational self-with-other schemas, which increases cognitive processing, relationship-centred anxiety and are emotionally mediated. Thus, the feedback loop based upon additional processing leads to the reappraisal of ambiguous bodily stimuli and the activation of differing illness specific coping strategies (which are discussed later in this Chapter).

Figure 6.1

A Proposed Adapted Version of CSM in the Context of Ambiguous Symptom Recognition (reproduction of chapter four model)



* The green shading represents the novel concepts integrated into the CSM model as part of the findings of this thesis.

The above in turn expands upon CSM with regards to how people's personal characteristics (outside of lifestyle activity, previous illness, and treatment) in connection to the normal functioning self or situational stimuli (lay information, expert information, somatic/ symptomatic information) shape symptom recognition or the activation of illness and emotional representations (Leventhal et al., 2016). The findings and adapted version of CSM offer a unique perspective upon the processing of ambiguous bodily stimuli in health psychology which incorporates the role of relational factors (i.e., relationship-centred anxiety).

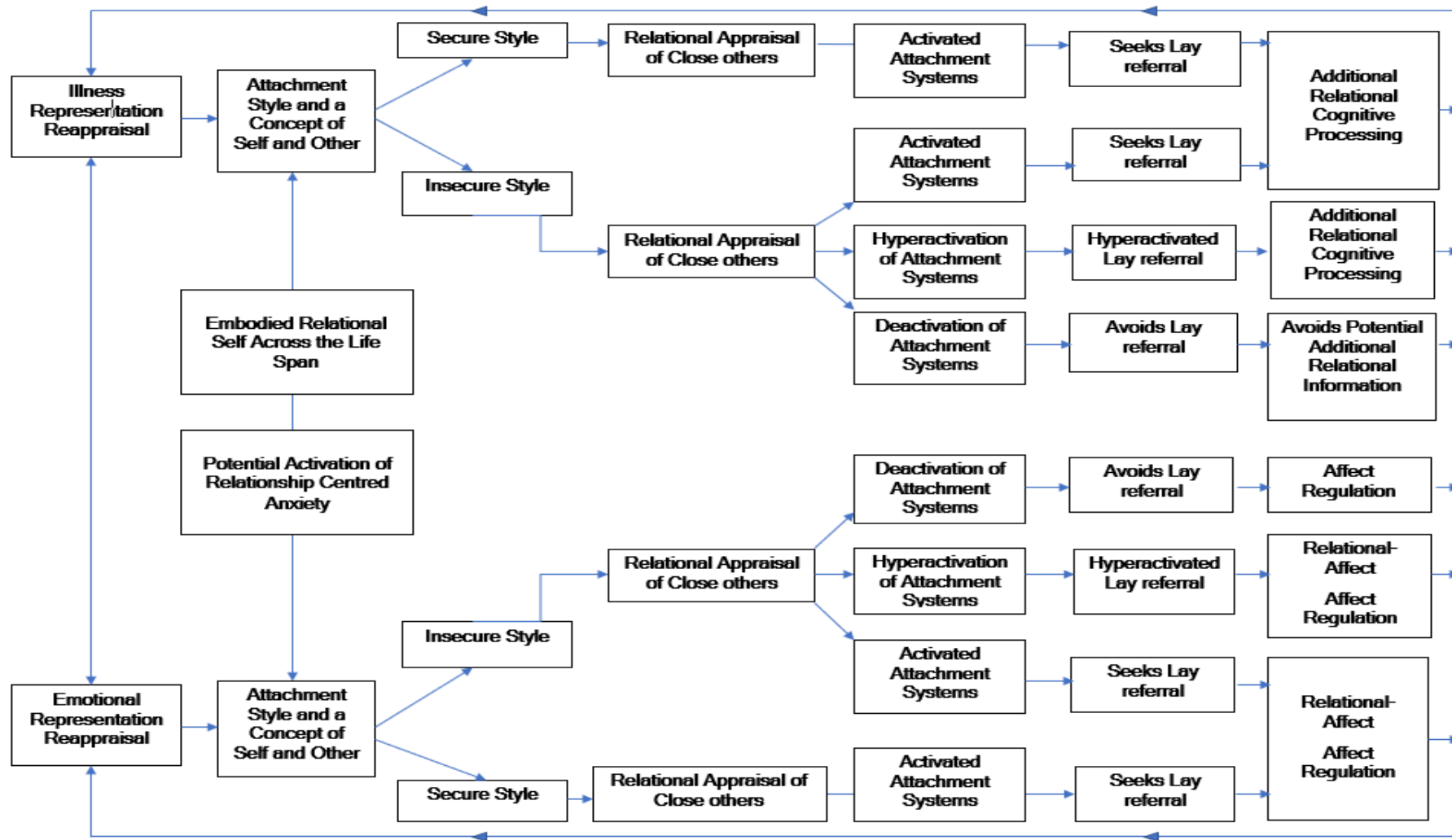
Emotional Coping and Lay Referral. The findings of the IPA study and the mixed and multi-method study contribute to the Model of Pathways to Treatment (MPT) in reference to the 'appraisal' and 'help-seeking' and CSM in reference to coping strategies. For example, Scott et al. (2013) outlined how people may cope, seek lay advice which may or may not lead to healthcare consultation; how social-cultural context is important, that symptoms may be noticed by others, how others may support people to make sense of their experiences, and that self-regulation is dependent upon input from others. However, what was not described MPT nor CSM is how previous life span experiences, the relational self, relational representations, schemas, attachment style, a concept of self/ other, and how secondary attachment systems may shape the process of affect-regulation, lay referral, and coping strategies when experiencing bodily changes.

It is therefore proposed based upon the findings of this thesis that the concept of lay referral moves beyond previous typologies (Freidson, 1970). Rather, it is suggested that both MPT and CSM could incorporate theories of interpersonal cognition and adult attachment theory as a lens through which to consider how people make sense of lay referral. This would not only add depth to our understanding of lay referral but also provide an illness specific or health threat specific component to CSM. This would provide an alternative perspective as opposed to the more generic coping strategies associated with 'seeking social support' linked with emotion and instrumental focused coping (Hagger et al., 2017). As part of this thesis, it is argued that although lay referral could be seen as 'seeking social support', the concept has evolved taking into account the role of the embodied relational self, relationship-centred anxiety, and people's attachment styles. This relational perspective in connection to lay referral offers insight as to why some

people may seek proximity during lay referral whilst others may not. The proposed evolved concept of lay referral developed throughout this thesis is presented for the first time below (figure 6.2) following a synthesis of Chapters four and five. This not only builds upon the existing literature but builds upon the concept described in Chapter four, demonstrating not only the evolving nature of the concept but the knowledge produced through the sequential methods used in the current studies. Therefore, figure 6.2 proposes an infusion of the experiential aspect of the participants' experiences and theory when bodily stimuli are non-salient, do not activate illness representations, or partially elicit illness prototypes. (The insecure attachment styles have been grouped as part of figure 6.2, see figure 6.3 for more in-depth information about the different adult attachment styles and lay referral based upon a concept of self and other).

Figure 6.2

A Proposed Contemporary Relational Conceptualisation of Lay Referral



The results of the mixed and multi-methods study usefully contribute to the conceptualisation of lay referral, with the findings indicating that some people experienced attachment systems activation in connection to hyperactivation and deactivation processes during the COVID-19 pandemic. These differing attachment systems presented themselves in different ways in Chapters four and five, but are important to consider. For instance, in the IPA study, it was inferred that when people appraise proximity seeking as unhelpful in terms of reducing distress, as part of the deactivation process people distance themselves and become dismissive in terms of the threat itself. Consequently, people express self-reliant attitudes/ reduce their need for support from others which was identified in the IPA study in terms of the acquisition of information online (i.e.- leukaemia vs. pernicious anaemia) which offered an accessible and available safe space to engage with problem-focused coping (Mikulincer & Shaver, as cited in Baldwin, 2005; Mikulincer & Shaver, 2009; Mikulincer & Shaver, 2020).

The role of attachment in the context of health psychology has previously been explored as described in Chapters three, four, and five. For example, Vilchinsky et al. (2015) investigated if attachment moderated the association between caregiver burden and symptoms of depression in a sample of 111 women whose partners had experienced acute coronary syndrome for the first time. Data was gathered at baseline, one month, and six months. Using structural equation modelling, the results identified that caregiver burden and depressive symptoms were influenced by greater attachment anxiety, but not attachment avoidance. This supported the authors' hypothesis and gave insight into how attachment may affect people's coping responses as do current findings reported in Chapters four and five. As part of the triangulation and interpretation of the findings reported in Chapter five, we see not only activation and deactivation of attachment systems but their hyperactivation. The fearful-avoidant group felt a sense of hypervigilance and health-related fear/ health threat for others, family members, and friends during the COVID-19 pandemic which increased their engagement with lay referral. This hyperactivation of attachment systems is important to consider as hyperactivated attachment systems involve increased vigilance to threat related cues and a reduced detection of the attachment figure's unavailability (Mikulincer & Shaver, as cited in Baldwin, 2005). The reduced detection of the attachment figure's unavailability is interesting in the context of self and other and offers insight to why people may still

seek proximity/ increased engagement with lay referral even if or when their concept of other may typically be negative. To give more insight into lay referral with regards to different adult attachment styles, figure 6.3 has been developed based upon the participants' narrative data from Chapter five. The participants' data has been integrated as part of a model of self and other (as originally developed by Bartholomew, 1990) and it is thought that this offers further insight into the experiential aspects of lay referral whilst also proposing the expansion of adult attachment in the context of health and illness.

Figure 6.3*A Proposed Model of Self and Other in the Context of Lay Referral*

Model of self in the context of lay referral following the perception of a low-to-medium health threat

| | Positive (low dependence) | Negative (high dependence) |
|----------------------------------|---|---|
| Positive (low avoidance) | Secure Continuously, typically, actively and engaging with lay referral. Responsive to other people's needs, with others being responsive towards them. Engagement with lay referral was perceived as support, provided comfort, emotional regulation, and relational affect. This relates to Bartholomew (1990) in terms of how the secure group expressed a sense intimacy and also autonomy. | Preoccupied Active, engagement with the process of lay referral although a level of avoidance was described, based upon the perceived relational consequences. The lay referee was perceived as responsive. This reflects and builds upon Bartholomew (1990) with reference to a preoccupation with relational aspects of lay referral. |
| Negative (high avoidance) | Dismissing Active, typical engagement with the process of lay referral. Whilst dismissive/ avoidant of lay referral based upon the expression of negative perceptions related to others in terms of other people's worries and judgments during the COVID-19 pandemic. This aligns with Bartholomew (1990) in connection to the dismissal of intimacy whilst expressing counter-dependence. | Fearful Engaged but were less likely to talk about their bodily changes whilst others were hyper-vigilant which increased lay referral. Avoidant of lay referral due to a fear of isolation and separation. This also relates to Bartholomew (1990) with regard to how this group talked less about intimacy whilst also socially avoidant. |

Model of other in the context of lay referral following the perception of a low-to-medium health threat

Help-Seeking and Professional Healthcare Advice. In terms of seeking professional healthcare advice, the current findings contribute to the MPT regarding the 'appraisal' and 'help-seeking' interval. Specifically, the findings highlight the complexity of professional healthcare help-seeking behaviours beyond that of decision making based upon competing priorities, expectations, system accessibility, and self-efficacy (the perceived ability to access professional healthcare advice) (Scott et al. 2013). Rather, the findings of the IPA study indicate that help-seeking is shaped through previous experience. For instance, for most who took part in (6 out of the 7) the IPA study, it was clear that their previous experiences of healthcare services were grounded negative, unhelpful, and ineffective healthcare-related interpersonal experiences. The mixed and multi-methods results also exemplified how the pandemic has influenced the participants' perceptions of healthcare service which had an impact upon their help-seeking behaviour. This thesis in turn contributes to our understanding of help-seeking behaviour through an attachment theory lens and relational perspective. The findings presented in this thesis indicate that the concept of self and the concept of other and people's interpersonal representations are not restricted to close others, romantic relationships, or significant attachment figures. Instead, the narrative data collected in Chapters four and five supports Mikulincer and Shaver (2020) in regard to how those in a formal role such as a manager, teacher or therapist, etc. (in this case a healthcare professional) can support or not support psychological functioning and in turn adapt or cope when people experience distress or health related threats. This was discussed in depth in connection to the activation of attachment systems, hyperactive and deactivated professional healthcare help-seeking behaviour in Chapters four and five. This leads to consider if those who experience insecure attachment styles are more at risk of deactivated coping strategies when faced with increased health threats which may increase the delay.

Overall Limitations

Limitations of The Scoping Review

Scoping reviews do not generally include an assessment of study quality in regards to the charted literature (Levac et al., 2010) due to the diverse range of

papers or chapters published across multiple disciplines, the use of different methods, and analysis in relation to the same topic. It is acknowledged that although this heterogeneity of studies and evidence could be seen as a limitation, it provides a useful opportunity to consider the charted literature from a critical position, to explore existing gaps in knowledge, and to build upon previous research. Other limitations in reference to scoping reviews relate to how labour intense the process of the review itself is. This generally reflects the intention of scoping reviews which purposively aimed to broadly scope the existing literature. The scoping review method has also met previous critique as they tend to provide a broad descriptive overview and discussion of the literature which may lack a higher level of interpretative synthesis in reference to the review findings (Sucharew & Macaluso, 2019). This critique arguably relates to other limitations in connection to the thematic analysis of the empirical key findings produced as part of this thesis. For instance, it is argued that thematic analysis as an analytical strategy lacks guidance in connection to interpretative analysis, and focuses on a cross-case analysis. This means that although the empirical key findings were considered in terms of similarities between the studies; it could be argued that aspects of the individual studies may have been lost (Braun & Clarke, 2013).

Limitations of The IPA Study and Design

As with all methodologies, methods, and analytical strategies, IPA presented some limitations. These limitations relate to a critique in connection to the smaller sample size (compared with larger samples or mainstream psychological experiments etc.) in which IPA could be considered by other perspectives to not hold substance (Braun & Clarke, 2013). The cross-sectional nature of the IPA study captured a snapshot in time. It is recognised that the sample's retrospective experiences may or may not change over time and that longitudinal approaches in qualitative research are increasing in popularity and are preferable to give a much richer and in-depth temporal understanding of the topic. Given the ideographic position of IPA, this study did not aim to be generalizable, nor did it aim to employ strategies such as data saturation. These concepts were not considered to be a meaningful goal of the IPA study given the ideographic focus, thus meaning that saturation would not ever be achieved. The stages of analysis could be viewed as

prescriptive as opposed to flexible depending upon the researcher, unlike thematic analysis, IPA does not have theoretical flexibility and it could also be argued that IPA lacks guidance upon the interpretative nature of the analysis. Other limitations outlined in the field have included those argued by Van Manen (2017) who suggested that IPA research on occasion can lack genuine phenomenological understanding. Here, Van Manen (2017) argues that these types of research should in fact be classed as psychological research. However, Smith (2018) offered an alternative position on Van Manen's (2017) paper, claiming that IPA has a valuable role in the context of health and illness research. Smith (2018) highlighted how reflexive accounts do contribute at a broader level to phenomenological research, as when people reflect upon an experience, the reflection itself becomes part of the phenomenon being explored. This links back to the above with regards to one of the key features of IPA in connection to 'experience' and how people are self-reflexive.

Limitations of The Mixed and Multi-Method Study and Design. Limitations associated with the mixed and multi-methods study include the cross-sectional nature of the design. For example, the cross-sectional quantitative component prevented any temporal comparison i.e., the process of change as part of people's experiences and/ or responses to their bodily changes were not captured, and thus any causal inferences can only be speculatively interpreted with caution. Another issue with the cross-sectional design is that there were no baseline measures in terms of adult attachment style and although attachment patterns have arguably been considered to be stable across the life course, they may also be considered to be dynamic/ with an opportunity for change across the lifespan (Duschinsky, 2021). Hence, why contextual factors linked to the COVID-19 pandemic, and multiple measures of adult attachment may have given more insight into any self-reported changes during the pandemic given potential traumatic environmental factors and relational/ social restrictions.

Other limitations relate to how affect was not considered beyond that of emotional representations specific to the perception of bodily changes. The rationale for not including affect measures is primarily related to the cross-sectional design given the transient nature of affect which may or may not reflect temporal changes in connection to elicited emotional illness representations pending how salient the bodily stimuli are. From a functionalist sociological perspective, another issue could

be that data was not gathered to allow for measures of socioeconomic status (i.e., income, social status measures, occupation), the reason for this was the study's idiographic position following the results of the IPA study in which socioeconomic status was not found as part of the participant's lived experience. Similarly, from a clinical psychology perspective, it could be argued that measures around sadness, fear, anxiety, depression, and/ or trauma may have been useful to enable a more in-depth understanding of the potential interconnected nature of previous experience, cognition, and emotion in the context of symptom recognition and lay referral. However, including these would have shifted the focus of the study to more clinical-oriented factors as opposed to the symptom recognition and help-seeking behaviour from a health psychology perspective. Limitations of the template analysis as part of the qualitative component could also include the cross-case analysis which lacks an ideographic approach and in turn may fragment the participants' accounts across the different groups as part of the comparative design (King, 2012). Limitations in reference to the Story Completion Task include how due to the nature of text narrative data collection, the depth and richness of the data may vary (as the researcher is not present to probe for more information unlike during face-to-face interviews, etc.) and that some participants may create stories that are not relevant to the research question because the 'story stem' is purposely ambiguous (Braun & Clarke, 2013).

Recruitment and Sampling Limitations

The IPA Study

In accordance with the IPA methodology (Smith et al., 2009), a small voluntary and purposeful sample was sought. The sample was reasonably homogeneous and was considered in terms of geographical location, the physical experience of bodily changes, and life history of bodily changes. The study did not aim to only recruit female participants, although only female participants volunteered through the recruitment methods outlined in Chapter four. Therefore, the sampling was not representative of other genders (i.e., males) and the findings only captured female lived experience. Despite this focus on female lived experience, it could

equally be argued that an all-female sample unintentionally aided the homogeneous nature of the sample which is in alignment with IPA sampling.

Given the focus upon a reasonable homogeneous sample in terms of the geographical location, this study did not aim to represent a diverse range of individuals from a variety of locations nor offers a cultural comparison but instead focused upon those in Wales. For example, 4 out of the 7 female participants were recruited through an exhibition stall which was held in one location in Wales across a certain period of time. Sampling through this type of recruitment offered an opportunity to rapport build with potential participants in the local community, nonetheless, it is recognised in accordance with the literature factors such as self-selection bias may have influenced recruitment uptake (Lavrakas, 2008). This could be considered a limitation as the sample was not randomly selected, with those who took part, opting into the study through personal choice and/ or interest in the research topic. Here, it could be suggested that the potential relevance of the personal interest in the research topic (i.e., health, illness, bodily changes, or help-seeking) could have shaped the information shared during the interviews and the research findings (Lavrakas, 2008). However, a counterargument is that although it could be suggested that the sample is not representative of the wider population, for the purpose of this study it was considered an advantage in relation to the methodology and the in-depth analysis which may not have been possible with a large sample or comparative design. Here, it is also acknowledged that the experience of bodily changes as opposed to a specific cancerous illness symptom could meet criticism as the participants were not matched in terms of their specific illness symptoms but instead experienced a spectrum of bodily changes.

The Mixed and Multi-Methods Study

As discussed in Chapter five, this study was designed during the COVID-19 pandemic. The COVID-19 pandemic influenced several aspects of this study including the methods of data collection, recruitment, and the timescale. Each of these areas were all adapted due to the COVID-19 pandemic. These adjustments enabled the study to continue although brought several limitations. The first adaption in light of the COVID-19 pandemic was that the study needed to take place online

rather than face-to-face due to safety regulations. Here, the original plan had been to conduct data collection at multiple Primary Care and General Practice settings. The rationale for onsite face-to-face data collection was to recruit a homogenous sample of those who may have been experiencing a range of bodily changes and/ or classically well-known cancer symptoms before healthcare consultation. Every effort was made to recruit through several different online platforms to capture a more homogenous sample which would include those who may have been experiencing an increased health threat or cancer symptoms. For example, online recruitment was supported by charities such as Tenovus Cancer Care, The Tenovus Research Team, Tenovus social media, Friends of Tenovus, Breast Cancer Now, and Wales Cancer Alliance (amongst others as outlined in Chapter five). However, online recruitment uptake was slow during the pandemic and for this reason, an ethics amendment was submitted to Bangor University. The amendment was approved, this included an extension in terms of the duration of data collection and an adjustment to recruitment which involved the Bangor University Student Participant Panel (SONA).

The additional time frame agreed by the ethics panel and SONA as a recruitment method enabled the study to continue during the COVID-19 pandemic. However, limitations arose in regards to sampling through SONA, this included a high female student population with 81.7% of the sample being female and 73.4% 25 years old and under. This could have arguably produced sampling bias in terms of the study (and the LRM); with data not representative of people across different life stages nor genders, and questions the generalizability of the findings to the wider population. Finally, as discussed in Chapter five, the participants self-reported an overall low to moderate mean rank score in reference to their perceived health threat. This highlights that although every effort was made to recruit people who may have been experiencing an increased health threat or potentially cancerous illness symptoms, recruitment uptake was challenging during the COVID-19 pandemic. Here, it could be suggested that given the overall low to moderate perceived health threat that the participant's illness perceptions and subsequently their attachment systems were not activated hence the non-significant quantitative results. The researcher also considered the impact of the pandemic upon people's illness schemas, illness perceptions, how social restrictions or isolation may have

influenced the process of lay referral, and professional healthcare seeking behaviour. In consequence, it is suggested that the results of the statistical analysis should be interpreted with caution given the above issues.

Future research in light of the limitations

To build upon the IPA study, it is suggested that additional recruitment methods could be used to reduce any effects upon the findings due to potential self-selection bias. Future research could also explore different sample populations such as other genders (i.e., male, non-binary) in different geographical locations or countries, and with those who experience differing cancer symptoms. A qualitative longitudinal design would also offer more temporal insight into the topic of bodily changes, emotional coping responses, lay referral, and help-seeking behaviour. Similarly, future research in connection to the mixed and multi-methods study could consider a longitudinal design, with face-to-face recruitment outside of the COVID-19 pandemic. This may reduce any issues with recruitment uptake, allow different sample populations to take part and those who experience a range of differing perceived health threats in connection to bodily changes which may or may not be cancerous illness symptoms. The inclusion of different sample populations outside of the COVID-19 pandemic would allow researchers to test the extended symptom recognition model and to further develop the lay referral model formulated as part of this thesis. Longitudinal measures of affect, health-related anxiety, or anxiety, and depression could also be integrated into the design. This would enable the measurement of temporal change in connection to the role of emotion elicited through the experience of bodily changes and cancer symptoms.

Implications for Policy, Recommendations and Interventions

A Relational Evidence-Based Educational Healthcare Consultation and ‘Safety Netting’ Training Package

As described in Chapter One, cancer is the second leading cause of death globally and accounted for approximately 10 million deaths in 2020 (WHO, 2021). The National Institute for Health and Care Excellence (NICE) (2021) indicates that cancer has a significant affect upon both the individual and people who are close to

them, with over 300,000 cases diagnosed each year in the UK over 200 types of cancer. Cancer types are different with on occasion, different overlapping symptoms, for example, general symptoms may include unexplained pain/ aches, night sweats, unexplained weight loss, fatigues. Whereas, type specific symptoms include, for instance, abdominal pain, bloating or an increase in abdomen size, loss of appetite may indicate ovarian cancer (Cancer Research UK, 2021). This highlights the varying nature of symptom presentation. The findings of this thesis indicate that those who experience ambiguous, fleeting bodily changes which may or may not be cancerous illness symptoms sometimes gain healthcare professional advice. For those who did gain advice, they articulated a sense that their individual needs (physical, emotional, and/ or relational) went unmet, which on occasion heightened a lack of trust in regards to gaining healthcare advice. This is an important aspect of healthcare consultation in terms of the patient-doctor relationship although, given the variety of symptoms which may or may not be cancerous symptoms, the challenge in diagnosis or referral becomes apparent for those healthcare professionals working in primary care itself.

Current NICE guidelines (2021) offer a range of referral pathways for investigation following the recognition of potential cancer symptoms as discussed in Chapter one. Given the findings of this thesis in connection to the experience of bodily changes which may or may not be cancerous illness symptoms, the focus of the below recommendations will explore current guidelines in reference to ‘safety netting’ (as discussed in Chapter one) and how the results of this thesis could contribute to the NICE guidelines (2021) and applied clinical practice. The explicit focus upon ‘safety netting’ is because the existing guidelines offer suggested ways in which to provide patient information and support to those with ‘suspected cancer’ but not in terms of ‘safety netting’. These guidelines for healthcare professionals when interacting with those who experience ‘suspected cancer’ and their families, refer to decision making options in relation to their referral to other services, reassurance, possible diagnosis, and service expectations. However, there is no clear guidance to support primary care in reference to their interactions with people during the ‘safety netting’ phase of clinical care.

Safety netting has been outlined in the NICE guidelines (2021) as a way in which to actively monitor people who experience symptoms across two domains. The first relates to timely review and post-investigation action. The second refers to

active monitoring for those who are low risk (not, no risk) and managing this risk. Here, the focus is upon the healthcare professionals to review, take the appropriate action, or pass patients to another professional. Reviews are also recommended to be planned (patient-initiated) with the person, if the person experiences new symptoms, if the person continues to be concerned, or if the symptoms reoccur, persist, or become more severe. However, in accordance with Cancer Research UK (2020), not every GP practice has a safety netting protocol in place although Macmillan Cancer Support (2021) has developed an e-learning course aimed at GPs. Safety netting to monitor those who experience bodily changes that may or may not be cancerous illness symptoms is currently being explored as part of a new feasibility study in Wales (Disbeschl et al., 2021). The study includes an intervention that aims to increase timely diagnosis through teaching/ awareness sessions, the integration of a 'safety netting champion', and the development of a safety netting plan that has been adapted for remote delivery. The findings of this study will inform an ongoing and new trial in Wales (Disbeschl et al., 2021).

However, to build upon the findings of this thesis from a psychosocial, interpersonal, and relational perspective; the overall recommendations relate to a relational informed approach to safety netting practice and healthcare consultation. A relational perspective to communication during this period and/ or consultation could hold both value in connection to national/ local policy and applied practice interventions or psycho-educational packages for healthcare professionals. A relational informed approach to safety netting practice and healthcare consultation would be grounded in psychological theory to support the relational nature and the potential need for repeated interactions, consultations, and potential diagnosis (or not) which may continue across a certain period of time. This would have a particular focus upon the ambiguous nature of varying symptoms or the fleeting experiences of bodily stimuli and would aim to address the issues raised in terms of the patient-doctor relationship and service user's perceptions of healthcare services which on occasion has reduced engagement. It is recognised that ambiguity can present challenges for both service users (as found here) and healthcare professionals themselves in terms of decision-making, referrals, diagnostics, and clinical practice. Therefore, the aim of a relational informed approach to safety netting practice and healthcare consultation would specifically focus upon 'patient communication' moving beyond that outlined by Cancer Research UK (2021). This approach would

raise awareness of the challenges service users may encounter, recognising, emotionally/ socially coping with bodily changes and offer an opportunity to explore professional healthcare communication and responsiveness as part of the consultation process. This could relate to the interpersonal process that potentially takes place during both clinician and/ or patient-initiated consultation when people experience bodily changes that may hold no clear diagnosis. Issues around the potential of increased negative affect during and/ or beyond consultation could be considered and how best to support people who fall within the 'safety netting' protocol, and how best to support people to gain access to the relevant services during this period. Empirical evidence related to adult attachment theory would also be investigated in connection to people's potential coping responses/ affect-regulation (i.e. hyperactivated or deactivated responses) following a 'safety netting' procedure being implemented. This would enable healthcare professionals with knowledge of people's (patient) history (i.e., previous close or wider experiences of relational adversity as found in this thesis, etc.) to consider how they will manage 'safety netting' in partnership with patients (Maunder & Hunters, 2015). This would take into account individual differences associated with potential service engagement, increase patient-initiated healthcare consultation, and avoidance, which may create further diagnostic delay and referral to other investigative healthcare services.

A relational informed approach could specifically focus upon interpersonal exchanges and/ or 'patient communication' building upon the work of Mikulincer and Shaver (2020) as outlined in the book chapter *'applications of attachment theory and research; the blossoming of relationship science'*. Mikulincer and Shaver (2020) outlined how illness may elicit distress which activates attachment systems and in consequence people's concepts of self and other which is directed to those who may be able to decrease these emotions. Interestingly, it is also proposed that doctors and healthcare staff may be perceived as a safe base in which expert knowledge can create safety and healing. Therefore, Mikulincer and Shaver (2020) suggest that service users may appraise healthcare professionals as fulfilling (or not) attachment figures. This highlights the potentially significant role that healthcare professionals have in terms of responsiveness when people seek advice which may influence their experience of fear/ distress, engagement with services, treatment, and their overall recovery (Maunder & Hunters, 2015). Mikulincer and Shaver (2020) conclude that

although there is evidence of the role of attachment there is no research to date that considers the role of healthcare professionals, their responsiveness, and how this influences, or manages people's emotions during recovery from illness. However, it is thought that this thesis does contribute to this area of research and offers the basis for future research in terms of how the relational self, relationship-centred anxiety, relational schemas, relational-regulation/ affect-regulation, and attachment style shape people's perceptions, lay referral, and help-seeking behaviour. In addition, Mikulincer and Shaver (2020) indicate that there is currently no evidence-based training or medical education that explores the role of relational factors in the context of healthcare provision and communication.

Given the findings of this thesis, and the collective evidence that indicates the role of attachment during periods of a health threat, the role of the patient-healthcare professional relationships; the ambiguous nature of potential cancerous illness symptoms, and the recommendations of NICE guidelines in terms of 'safety netting', it is suggested that a feasibility study is conducted with regards to an evidence-based educational training package could be developed for (or in conjunction with) healthcare professionals. A feasibility study would enable the exploration of the acceptability, the demand, implementation, practicality, adaptation, integration, and expansion of such a package (Bowen et al., 2010). In turn, this educational training package would provide a framework to enhance the recommendations in terms of 'patient communication' by Cancer Research UK/ the NICE guidelines (2021) during periods of 'safety netting' from a relational perspective. This could potentially offer healthcare professionals a space in which to develop responsive communication when people experience distress and fear. Here, it is important to recognise that the above is suggesting something different than what has already been described in the literature in terms of the role of empathy and/ or compassion in patient care (see Sinclair et al., 2016; Howick et al., 2018) with a relational understanding offering insight to how people's previous relationships, life span experiences, cognition, and emotions may shape their interactions and help-seeking.

Another important aspect of this work could be in relation to supporting professionals to understand that insecure attachment is not a disorder and that it is part of '*normal psychology*' with all people experiencing certain patterns of attachment including healthcare professionals themselves (Maunder and Hunter, 2015). For example, Maunder and Hunter (2015) indicate that insecure attachment

when understood from a developmental perspective suggests a relational style that experiences compromises, in which people tend to compromise between maintaining their relationships whilst reducing difficulties or problems that arise as part of the relationships themselves. Therefore, the educational training package could be based upon the evidence outlined as part of the studies included in this thesis and the previous literature (Maunder & Hunter, 2015; Mikulincer and Shaver (2020). This aligns with the Welsh government 'Quality Statement for Cancer' 2021 (as discussed in Chapter one) in terms of providing person-centred care that assesses and manages people's needs. The only difference here would be that although the educational package would support 'person-centred' care it would also indicate a shift in current thinking from 'person-centred' to 'relational healthcare' (Maunder & Hunter 2015). Thus, highlighting a relational focus that human relationships are not about individuals, but all of those involved, including when people interact and/ or engage with healthcare professionals.

The suggestion of relational healthcare is important, Maunder and Hunter (2015) outline a number of ways in which this could be applied including giving advice to service users, etc. This is particularly relevant in connection to the recommendations of this thesis in connection to the role of attachment and 'safety netting'. For instance, Maunder and Hunter (2015) discuss working with people who are high in attachment avoidance and how good working relationships that require a level of trust can lead to healthcare professionals supporting service users to interact with other professionals when needed. They indicate how professionals could (amongst other applied suggestions):

- Maximize effective self-management through acknowledging problems when they exist
- Negotiate and collaborate
- Guard against minimizing symptoms and underusing healthcare (Maunder & Hunter 2015).

Another interesting aspect of Maunder and Hunter's (2015) 'Love, Fear, and Health; How Our Attachments to Others Shape Health and Health Care' book is that they recommend ways to work with people who may experience a fearful-avoidant attachment style. This is of particular relevance given the results of the mixed and

multi-methods study that identified the deactivation of attachment systems which led to avoidance. Therefore, although the above approach incorporates relational factors such as compassion, it also offers an alternative perspective that integrates an understanding of how people's previous experience, cognition, and emotion influence their relational interactions with reference to responsiveness. It is also acknowledged that this type of package may not only be useful in the above proposed context but could also be adapted and delivered to a wide variety of healthcare professionals during mandatory training and/or during university-level education.

Relational Healthcare and Public Health Messages About Bodily Changes That May or May Not Be Cancerous Illness Symptoms

As part of Chapter one, the importance of classically well-known cancer symptoms in reference to current policy, campaigns, and clinical practice was outlined. The significance of encouraging people to seek healthcare advice for 'vague' and/ or 'unexplained symptoms' was also identified in Chapter one. However, following the findings from the empirical studies (Chapters four and five) and in particular the IPA study with reference to the sub-theme of *'health and illness as an experiential ambiguous continuum'* and how the perception and recognition of bodily changes arose across an experiential continuum of both physical and emotional changes, it is clear that people may not recognise 'vague' bodily changes as illness symptoms. This questions the feasibility of increasing people's perceptions or raising people's awareness of non-specific cancer symptoms or 'vague' bodily changes as people's illness representations may not reflect the level of risk associated with this line of thought. Hence, it is suggested that public health messaging instead (or in addition to) aims to increase perceptions of risk in reference to non-specific cancer symptoms, taking more of a relational approach. This approach that incorporates interpersonal factors has been described by Maunder and Hunter (2015) who indicate that messages such as: '...smoking kills' may not hold as much power as 'that your children need you around'. This is an interesting and complex area of work although discussions around the effectiveness of public health messaging, the approaches, and the discourse used, are beyond this thesis/ the researcher's area of

work and have been included as a recommendation for potential future lines of inquiry.

An Adaptable Digital COVID-19 Emotionally Focused Educational Intervention for Those Experiencing a Potential Health Threat

Given the potential impact of the COVID-19 pandemic in terms of potentially creating traumatic stressors, creating anticipated fear of loss, and the multifaceted challenges the pandemic has created in terms of access to healthcare services (as discussed in the results of Chapter five), a digital COVID-19 emotionally focused educational intervention is recommended. Here, it is acknowledged that the educational intervention would not need to be conducted online, although it could potentially be adapted online in the future due to the pandemic which would support access to services and reduce barriers. It is also recognised that this recommendation is not intended for a clinical psychology population, but for people who may be experiencing a health threat and/ or their family members or close others. Hence, it is suggested that people may benefit from a package that supports relational learning with regards to how people may respond, behave, think or feel when they or someone they know may experience a health threat.

- For dyads, and those in close relationships, as a way supporting people in their relationships when they are coping with ‘safety netting’, the early diagnosis of cancer during COVID-19 and/ or treatment in hospital. The relevance of the COVID-19 pandemic is extremely important as the separation between close relationships may occur due to hospital restrictions during diagnostic tests/ treatment etc. This potentially heightens anxiety, fear, and separation distress when engaging with healthcare services and relational adversity between close relationships
- An educational parental (potentially digital in light of barriers experienced during COVID-19) emotionally focused intervention could be adapted and developed for parents when a member of the family is undergoing ‘safety netting’, diagnostic investigations, and/ or treatment to support parents when communicating with their children, siblings, and others

- A version to help young people understand potential emotional responses, people's behaviour, thoughts, etc when a loved one is undergoing 'safety netting', diagnostic investigations, and/ or treatment. Here, it is recognised that young people from a developmental perspective are not adults and therefore, require a tailored intervention that is cognitively, emotionally, and communicates appropriately with this age group. This expands upon the recent 2021 guidelines published by the National Institute for Health and Care Excellence (NICE) in reference to working with babies, children, and young people when thinking about their experience of healthcare (NICE, 2021)
- A child intervention that incorporates developmentally appropriate approaches such as social stories as a way in which to present and prepare children for a family member undergoing diagnostic investigations and/ or treatment. This could prepare children for periods of separation whilst family members engage with healthcare services. The proposal of a developmentally appropriate version is based upon the findings of Chapter four which demonstrated how people draw upon life span experience when making sense of the present.

The Relevance of a Digital Strategy During the COVID-19 Pandemic and Beyond

Although not paramount and suggested in light of the COVID-19 pandemic due to barriers and restricted access to services (as discussed in Chapter five) the above fits with the NHS Digital (2019) guide. The document is an inclusive guide for health and social care with the aim of delivering information and services digitally whenever appropriate. This increases access to information, care from a service user's perspective and also potentially creates more effective delivery, which could reduce costs and people's poor outcomes. Therefore, not only does the proposal of a digital emotionally focused intervention meet the current NHS strategy, the challenges of COVID-19, but it is also in alignment with recent research regarding psychological interventions. For example, Boulley et al. (2018) conducted a systemic review that examined people's engagement with and the psychosocial effects of

digital health interventions when people are living with cancer. The research included in the review came to a total of 24 studies. The results found a high level of engagement with digital interventions with self-efficacy, quality of life, and measures of psychological symptoms generally been captured. The review concluded that although differences arise in terms of the results of each of the interventions, digital interventions offer a good way to support people coping with cancer.

The Relevance of an Educational Emotionally Focused Intervention and Attachment When People Experience Bodily Changes

The relevance of an educational emotionally focused intervention is based upon the findings of the empirical studies (Chapters four and five) which found that people experienced a spectrum of emotions whilst experiencing non salient bodily changes. The above is proposed to support people emotionally within their relationships when they or someone else is experiencing a health threat. For instance, The American Society for Clinical Psychologists (Society of Clinical Psychology, 2016) outlined emotionally focused therapy for couples (EFT) as an attachment oriented intervention that considers the potential negative, sometimes inflexible interactions and patterns which arise between people. These relational patterns may involve negative affect, distress, emotional disconnection, and insecure attachment. Hence, why this approach is suggested as the participants in the IPA/ the multi and mixed methods study expressed challenges in their relationships. The premise within EFT is that change arises neither from insight nor improved skills, but from the expression of alternative or new emotional experiences that change interpersonal interactions, attending to people's attachment needs and emotions. EFT draws upon a systemic and humanistic perspective to cultivate an increased secure attachment within people's relationships and for partners to be emotionally accessible, responsive, and engaging, to help their partners when they are distressed. A basic overview of the EFT process is outlined below, although it is recognised that the processes related to therapy are much more in-depth and outside of the scope of this thesis and again have been suggested as a recommendation for the future:

- Stage one

De-escalation to support people understand how negative exchanges create a self-reinforcing cycle of distress linked to attachment.

- Stage two

The restricting of interactions, creating alternative emotional experiences and exchanges which lead to an increased secure connection. It is encouraged that people explore and share their relational needs and attachment vulnerabilities with their partner through focused and structured enactments, thus developing new cycles of interactions and caring.

- Stage three

Consolidation supports people to draw upon their more secure relational functioning to support them to solve issues, a sense of resilience, and mastery in the relationship.

There have been several clinical trials in terms of EFT in connection to a range of different areas such as EFT for couples in treatment for depression (Dessaules et al., 2003); EFT marital interventions for those who have children who experience chronic illness (Walker et al., 1996); and for those with advanced cancer and their spousal caregivers (McLean et al., 2008). Research by McLean et al. (2008) evaluated an 8-week EFT intervention with 16 couples that aimed to improve marital functioning for those who experienced advanced cancer and their spouse. Measures used included: the Revised Dyadic Adjustment Scale, Beck Depression Inventory, Beck Hopelessness Scale, and data was gathered at the baseline (T0), after the fourth session (T1), the eighth session (T2), and at three months post-intervention (T3). Data indicated (amongst other results) an improvement in Revised Dyadic Adjustment Scale scores for 87.5% of the sample from baseline to T2 in connection to marital functioning, and decreased scores on the Beck Depression Inventory from T0 to T3. McLean et al., (2008) concluded that EFT for couples may facilitate improved functioning in the marital relationship and relational growth across end-stage cancer. This highlights the role of EFT in the context of this thesis, but also how EFT could be drawn upon at earlier stages of the investigative, diagnostic, treatment, and end of life time frame to help families adjust and cope during this difficult time.

Future Directions

The recommendations for future research are that research should continue to take a psychosocial position and a theoretically integrated perspective to the topic of symptom recognition, differing coping responses, and help-seeking behaviour. This could include the below suggestions:

- From an inductive IPA qualitative perspective, studies could be conducted with a longitudinal design, with more diverse samples of people who experience bodily changes. For instance, a male sample, a gender diverse or non-binary sample, different cultures/ethnic groups, socioeconomic status, or with people who experience mental health issues or who have received a particular cancer diagnosis. This would give a more in-depth understanding in regards to moderate to high health threats
- Dyadic qualitative research between the person who experiences bodily changes or cancerous illness symptoms and the lay referent could examine the relational dynamic across different relationships to investigate the role of lay referral. For example, parent-child relationships, romantic relationships, friendships, professional relationships (i.e., those who may fulfil the attachment figure role). The relational mapping interview could be used from each person's perspective (Boden et al., 2018).
- An alternative IPA study could further explore healthcare professionals' experiences of consultation with service users who experience bodily changes to investigate the doctor-patient relationship. This would provide an alternative perspective of consultation with reference to bodily changes which may or may not be cancerous illness symptoms. Alternatively, a comparative template analysis could be used across a larger sample to explore how attachment style influences healthcare professional perspectives of those accessing services who experience ambiguous bodily changes and if this shapes interpersonal interactions during consultation.

- The novel pluralistic mixed and multi-method approach that encompassed the story completion method, photo elicitation, and template analysis, could also be re-applied with a longitudinal design. This would enable the measurement of affect, anxiety/ depression with those who have recently experienced a range of moderate to high health threats or cancerous illness symptoms. This would build upon the findings reported in this thesis and enable an exploration of how attachment systems influence coping, affect responses, and help-seeking behaviour. Here, the focus could be upon when people experience an increased health threat that may have life-threatening consequences. Further investigation in connection to mediation analysis is also recommended
- Further development of the proposed adapted version of CSM specifically in the context of ambiguous and non-salient bodily stimuli
- Further development of the proposed contemporary and relational conceptualisation of lay referral
- The application and exploration of the proposed contemporary and relational conceptualisation of lay referral with people across different sample groups. It is recommended that the sample groups differ in terms of health threat severity including those who experience a high level of threat. This would enable the exploration of how attachment systems function and potentially offer a comparison with regards to the findings of this thesis
- The exploration of public health messaging from a relational healthcare perspective
- The development of a health campaign from a relational perspective that takes into account the findings of this thesis with regards to how people recognise bodily changes as illness symptoms (or not) to encourage the earlier diagnosis of cancer
- A systematic review of the literature in terms of EFT interventions across the lifespan

- The design of an online version of an EFT educational intervention for the differing sample populations as outlined earlier in the chapter taking into account age-appropriate and developmental approaches
- The implementation of a feasibility EFT study across the different sample populations.

A Return to Reflexivity

How knowledge is produced and understood through differing methods has been a rich learning journey across my adult education. My understanding of epistemology and ontology started during my undergraduate degree in psychology. For instance, I studied mainstream positivist approaches and critical social psychology that incorporated Phenomenology, Discourse Analysis, and Psychoanalytical approaches. Here, it was through learning about positivism, interpretivism, and constructivism (amongst others) that I started to gain an appreciation for the existence of ‘multiple truths’. I remember feeling inspired by learning about how different frameworks provide different ways of understanding the phenomena being explored and that the same topic can be understood from multiple perspectives. Therefore, when reflecting upon my epistemological growth, it is no surprise to me that I immersed myself in new learning which built upon my BSc and MSc during my PhD which increased both my learning and meta-cognitive thinking skills.

This new learning during my PhD related to pragmatic approaches in healthcare research, contextualism in reference to my IPA study, and pluralism as part of my mixed and multi-methods study. The opportunity to read, learn and apply these different frameworks to my work offered rich learning in terms of knowledge production and study design. For example, I feel that my understanding of symptom recognition, emotional coping responses, lay referral, and help-seeking behaviour were accelerated through the different epistemological frameworks across the thesis. I found reading about pluralism particularly exciting, as pluralism offers an invitation to consider how different epistemological frameworks conflict, complement or may co-exist together. This provided at times a complicated, challenging but interesting

space in which to learn. I believe it was through engaging with pluralism that my epistemological growth accelerated and was nurtured. I held differing approaches together, worked with them, developed my skills in terms of study design, data collection, and how to draw upon several types of analysis. This was particularly interesting when engaging with the triangulation process as part of Chapter five.

My interest in mixed methods research that started during my MSc also shaped how I approached my PhD. This can be exemplified when considering the exploratory approach to the overall design that drew on different methods sequentially, to inform the design of the proceeding study. I also embarked upon learning about qualitative multi-methods research. This was equally exciting in the sense that I was able to engage with a research design that had multiple components which at times complemented each other. This took considerable time and I found the second-level reflexivity very helpful to support this process. The depth of learning that I have encountered bringing Chapters of the thesis together felt incredible. I am very grateful to have encountered pluralism and had the opportunity to work in this way. The integration or combination of mixed and/ or multi-methods is where my passion now sits alongside, relational factors, and health psychology. For me, the integration or combination of methods facilitated a level of creativity, and as a creative person, I did and still now do feel drawn to this way of working.

As a researcher, the PhD journey has been one of challenge and immense personal and professional learning. The learning that has occurred has not just been about my academic output but also about my identity as a researcher. I am wholeheartedly aware of how I can contribute to research and where my strengths and weaknesses lie. This has been one of the greatest learning experiences of my life, and I absolutely love conducting research. Ten years ago (in 2011 when I started studying psychology part time whilst working full time) a friend said to me *“if you can find a job that you love, it feels less like work”*, and I now feel I have found it as an academic.

To add an element of creativity into my work, I included some artwork to express how I felt at certain points when designing the mixed and multi-methods Chapter. I feel that these images captured a process, almost a snapshot of where I was at in terms of the research process. However, when reflecting upon the overall PhD process as a whole, these images reflect a moment that is almost symbolic of

my own situated knowledge. For instance, they don't capture the essence of my progression, learning, and academic growth as a researcher. Therefore, when taking some time to think about it, I feel it is important to acknowledge change, change in the context of my learning, knowledge, me as a professional, and how this has been an evolving journey over several years.

Conclusion

This thesis offers a novel unfolding contribution to the field in terms of how people recognise bodily changes as illness symptoms (or not) as opposed to classically known cancer illness symptoms as defined by the medical model. In connection to symptom recognition, the concepts of self-with-others schemas, the role of relationship-centred anxiety, emotionally mediated interpretation, and the reappraisal of ambiguous/ non-salient bodily stimuli were integrated into the CSM model. This conceptual integration offers a new way of understanding symptom recognition which incorporates the role of relational factors and emotion. The concept of lay referral and healthcare seeking behaviours also underwent considerable conceptual development which built upon the existing literature through people's lived experience of bodily changes and during the COVID-19 pandemic. Here, the multifaced nature of lay referral and professional healthcare seeking was apparent which highlighted the role of people's previous interpersonal familial, close relational, and healthcare experiences. These areas were theoretically contextualised to encompass the embodied relational self, attachment related cognitive schemas, relational appraisal, relational-affect activated responses, affect-regulation, and the reappraisal of illness representations following engagement or avoidance of lay referral and help-seeking. Therefore, this thesis has integrated several different concepts and theories in order to move beyond previous dualistic ways of understanding these processes from a relational perspective.

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Appendices

Appendix B

(Mixed methods appraisal tool) (2018)

Part I: Mixed Methods Appraisal Tool (MMAT), version 2018

| Category of study designs | Methodological quality criteria | Responses | | | |
|--|---|-----------|----|------------|----------|
| | | Yes | No | Can't tell | Comments |
| Screening questions (for all types) | S1. Are there clear research questions? | | | | |
| | S2. Do the collected data allow to address the research questions? | | | | |
| | <i>Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i> | | | | |
| 1. Qualitative | 1.1. Is the qualitative approach appropriate to answer the research question? | | | | |
| | 1.2. Are the qualitative data collection methods adequate to address the research question? | | | | |
| | 1.3. Are the findings adequately derived from the data? | | | | |
| | 1.4. Is the interpretation of results sufficiently substantiated by data? | | | | |
| | 1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation? | | | | |
| 2. Quantitative randomized controlled trials | 2.1. Is randomization appropriately performed? | | | | |
| | 2.2. Are the groups comparable at baseline? | | | | |
| | 2.3. Are there complete outcome data? | | | | |
| | 2.4. Are outcome assessors blinded to the intervention provided? | | | | |
| | 2.5. Did the participants adhere to the assigned intervention? | | | | |
| 3. Quantitative non-randomized | 3.1. Are the participants representative of the target population? | | | | |
| | 3.2. Are measurements appropriate regarding both the outcome and intervention (or exposure)? | | | | |
| | 3.3. Are there complete outcome data? | | | | |
| | 3.4. Are the confounders accounted for in the design and analysis? | | | | |
| | 3.5. During the study period, is the intervention administered (or exposure occurred) as intended? | | | | |
| 4. Quantitative descriptive | 4.1. Is the sampling strategy relevant to address the research question? | | | | |
| | 4.2. Is the sample representative of the target population? | | | | |
| | 4.3. Are the measurements appropriate? | | | | |
| | 4.4. Is the risk of nonresponse bias low? | | | | |
| | 4.5. Is the statistical analysis appropriate to answer the research question? | | | | |
| 5. Mixed methods | 5.1. Is there an adequate rationale for using a mixed methods design to address the research question? | | | | |
| | 5.2. Are the different components of the study effectively integrated to answer the research question? | | | | |
| | 5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted? | | | | |
| | 5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed? | | | | |
| | 5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved? | | | | |

Appendix C

(Qualitative notice board poster)



Are you **living in Wales** and interested in taking part in a **research interview**?

Recognising and responding to bodily changes

About the interviews

The interviews will allow people an opportunity to discuss their own experience of noticing bodily changes, how this made them feel, who they spoke to about these changes and why. We are also interested in hearing about how these conversations made people feel and if these conversations influenced people's decision to go to the doctors or not. The interviews are planned to last no longer than 90 minutes and will be held on a voluntary basis.

Have you experienced any of the following:

Headaches, pain, bleeding, weight loss, lumps, tiredness, nausea, chest problems, abdominal issues or anything else within the last three months?

We are looking for:

- Men and women who are over the age of 18
- People who live in Wales

Signing up

If you would like to take part in an interview or would like further information please contact:

Emma Campbell on:

TELEPHONE **01248 383 515**

EMAIL **psp91a@bangor.ac.uk**

This study has been reviewed by and received ethics clearance through the Healthcare and Medical Sciences Academic Ethics Committee, Bangor University.



Ydych chi'n byw yng Nghymru a chyda diddordeb cymryd rhan mewn cyfweiliad ymchwil?

Adnabod newidiadau yn y corff ac ymateb iddynt.

Gwybodaeth am y cyfweiliadau.

Bydd y cyfweiliadau'n rhoi cyfle i bobl siarad am eu profiad eu hunain o sylwi ar newidiadau yn eu cyrff, sut y gwnaeth hyn iddynt deimlo, â phwy y gwnaethant siarad am y newidiadau hyn a pham. Mae gennym ddiddordeb clywed hwyf sut y gwnaeth y sgysiaid hyn i bobl deimlo ac wnaeth y sgysiaid ddylanwadu ar benderfyniad pobl i fynd i weld y doctor ai peidio. Ni fwnedir i'r cyfweiliadau bara mwy na 90 munud ac mae cymryd rhan yn gwbl wirfoddol.

Ydych chi wedi cael profiad o unrhyw rai o'r canlynol:

Cur pen, poen, gwaedu, colli pwysau, lymphiau, blinder, cyfog, problemau gyda'ch brest, poenau stumog/bol neu unrhyw beth arall yn ystod y tri mis diwethaf?

Rydym yn chwilio am y canlynol:

- Dynion a merched dros 18 oed
- Pobl sy'n byw yng Nghymru

Os hoffech gymryd rhan mewn cyfweiliad neu os hoffech ragor o wybodaeth, cysylltwch ag Emma Campbell ar:

FFÔN **01248 383 515**

E-BOST **psp91a@bangor.ac.uk**

Mae'r astudiaeth hon wedi cael ei hadolygu a chael ei chymeradwyo'n foesegol gan Bwyllgor Moeseg Academaidd Gwyddorau Gofal Iechyd a Meddygol Prifysgol Bangor.



Appendix D

(Qualitative participant information sheet)

CANOLFAN GOGLEDD CYMRU AR GYFER YMCHWIL GOFAL CYCHWYNNOL

NORTH WALES CENTRE FOR PRIMARY CARE RESEARCH



Recognising and responding to bodily changes

Version: 3

Participant information sheet

Phase one interviews

You are being invited to volunteer and take part within a research interview. However, before you decide if you would like to take part or not, here is some further information about what the interviews will involve. Please carefully read the following information and contact Emma on the details below if there is anything that you would like to discuss or if you would like any further information.

What is this project about?

This project aims to explore what factors influence attendance at healthcare settings such as the doctors, following people noticing physical changes in their body. Another area the project will consider is how people emotionally cope and how our friends, family or other people we know may influence the decision to gain healthcare or medical advice about these bodily changes. In order to explore this area, we will be conducting interviews with people who have recently experienced changes in their body and decided to seek healthcare professional or medical advice and with those who decided not to. The information gained during the interviews will then help to create a series of questions which will be used in a survey across Wales.

Do I have to take part?

It is entirely up to you to decide if you would like to take part or not in the interview. This information sheet has been provided to share further information and is for you to keep. If you decide to take part, we will also ask you to read and sign a consent form; you will be given a copy of the consent form to keep. However, it is also important to know that even after signing the consent form you are free to withdraw from the project at any time without giving a reason. Your decision to participate or withdraw will not affect the standard of care you receive from your local healthcare services.

What will I be asked to do if I decide to take part?

If you decide to take part, Emma will contact you and invite you to participate in an interview that will last no longer than 90 minutes. Emma will be leading the interview and during this time will invite you to discuss a range of areas including: your experiences of bodily changes, how this made you feel, if you spoke to anyone about these changes and whether or not this influenced your decision to go to the doctors. The conversations during the interviews will be informal and as relaxed as possible. The interviews will be held at a Bangor University campus (Wrexham or Bangor). A choice of times and dates will be offered.

Will my taking part be kept confidential?

All of the information shared in the project will be kept strictly confidential. Nevertheless, the research team are required by law to break confidentiality where cases of malpractice or risk to self or others are disclosed.

Discussions during the interview will be audio-recorded and written out (transcribed) after the session to allow the researcher to examine the conversations. It will not be possible to personally identify your comments from the transcripts, or in any subsequent verbal or written accounts of the interviews. The researcher will use another name or code when using your information from the interview (this may take the form of written quotes taken from the interview for presentations, conferences, in written work or publications). Recordings will not be heard by anyone other than Bangor University transcribers and researchers. The audio recordings will be transferred to secure password-protected computers and disposed of in accordance with Bangor University policy.

Will I be reimbursed for participating in an interview?

The interviews are voluntary and you will not receive any payment for taking part. We will reimburse reasonable travel expenses incurred.

What are the possible disadvantages and risks of taking part?

We do not foresee any disadvantages or risks of you taking part in this interview. However, a possible disadvantage is that participation will require a maximum of 90 minutes of your time. The interview questions have not been designed with the intention of changing any of your behaviour; rather the interview hopes to gain a deep understanding in relation to your previous experiences. However, should the discussion bring about any worries or concerns, we will encourage you to talk to your general practitioner or provide a contact information sheet with relevant support services.

What are the possible benefits of taking part?

Taking part in an interview will be an opportunity for you to express your experiences and why or why not you went to the doctors. Whilst there are no direct advantages to you personally, it is hoped that the information gained and the results of this project will help us understand why people seek healthcare professional advice and why some people do not. This in turn may lead to future research and contribute to policy makers knowledge in reference to people's perceptions about gaining medical advice.

What if something goes wrong?

We do not foresee any circumstance where you will come to harm by participating in this interview. Regardless of this, if you wish to complain about any aspect of the way you have been approached or are unhappy about any aspect of your participation, we would ask you to tell us in the first instance so that we can try to resolve any concerns and find a solution. Otherwise please follow the Bangor University complaints procedure.

What happens at the end of the research project?

The results of the study will be published in a scientific journal and will be submitted for presentation at relevant local and national meetings.

Who has reviewed the study?

This project was reviewed and approved by the Healthcare and Medical Sciences Academic Ethics Committee at Bangor University.

What should I do if I would like further information about the project?

For more information about this project, taking part in the project or if you hold any concerns please contact:

Emma Campbell

North Wales Centre for Primary Care Research
Bangor University,
Cambrian 2,
Wrexham Technology Park,
Wrexham,
LL13 7YP.

Tel: 01248383515

Email: psp91a@bangor.ac.uk

Emma Campbell is working under the supervision of:

Dr Julia Hiscock j.hiscock@bangor.ac.uk

Dr Becki Law, Professor Val Morrison and Professor Richard Neal

What do I do now?

If you return the reply slip Emma will contact you in the next few days to discuss any questions that you may have, to gain some information about yourself and to explain what happens next. Please also feel free to telephone Emma to ask any further questions or express your interest in taking part. If you agree to take part in the interviews you will be asked to sign two copies of a consent form at the interview. One copy of the consent form and this information sheet will be for you to keep. The second copy of the consent form will be retained by the research team

Thank you for taking the time to read through the details of this project.

For complaints please contact:

Professor Christopher Burton
School of Healthcare Sciences
Bangor University
Wrexham Technology Park
Wrexham
LL13 7YP

01248 382556

c.burton@bangor.ac.uk



Response slip

If you are interested in taking part in an interview please complete the details below, sign the form and send to the following address.

Emma Campbell

North Wales Centre for Primary Care Research
Bangor University,
Cambrian 2,
Wrexham Technology Park,
Wrexham,
LL13 7YP

Your details will only be used in connection with conducting interviews for this research and will only be seen by authorised members of the research team.

Name: _____

Address: _____

Town: _____

Postcode: _____

Daytime telephone number: _____

Email address: _____

I would like the research team at Bangor University to contact me to give me more details about an individual interview.

Signed _____ Date _____

Adnabod newidiadau yn y corff ac ymateb iddynt.

Fersiwn: 3

Taflen wybodaeth i gyfranogwyr

Cyfweliadau cam un

Rydych yn cael eich gwahodd i wirfoddoli a chymryd rhan mewn cyfweliad ymchwil. Fodd bynnag, cyn i chi benderfynu a hoffech gymryd rhan neu beidio, dyma beth gwybodaeth bellach am natur y cyfweliadau. Darllenwch y wybodaeth a ganlyn yn ofalus os gwelwch yn dda a chysylltwch ag Emma (manyllion cyswllt isod) os hoffech drafod unrhyw beth neu gael mwy o wybodaeth.

Project am beth yw hwn?

Bwriad y project hwn yw edrych ar ba ffactorau sy'n gwneud i bobl fynd i fannau gofal iechyd, megis i weld meddyg, ar ôl iddynt sylwi ar newidiadau corfforol yn eu corff. Maes arall y bydd y project yn ei ystyried yw sut mae pobl yn ymdopi'n emosiynol a sut y gall ein ffrindiau neu deulu ddylanwadu ar benderfyniadau i fynd i geisio gofal iechyd neu gyngor meddygol ynghylch y newidiadau corfforol hyn. Er mwyn edrych ar y maes hwn byddwn yn cynnal cyfweliadau gyda phobl sydd wedi gweld newidiadau yn eu corff yn ddiweddar a phenderfynu ceisio gofal iechyd proffesiynol neu gyngor meddygol, yn ogystal â phobl a benderfynodd beidio â gwneud hynny. Bydd y wybodaeth a geir yn ystod y cyfweliadau o gymorth i greu cyfres o gwestiynau a ddefnyddir mewn arolwg ar draws Cymru.

Oes rhaid imi gymryd rhan?

Mater i chi'n llwyr yw penderfynu a ydych eisiau cymryd rhan yn y cyfweliad neu beidio. Darparwyd y daflen wybodaeth hon i rannu gwybodaeth bellach ac mae i chi i'w chadw. Os penderfynwch gymryd rhan byddwn yn gofyn i chi ddarllen a llofnodi ffurflen gydsynio hefyd; fe gewch gopi o'r ffurflen gydsynio i'w chadw. Fodd bynnag, mae'n bwysig gwybod hefyd y gellwch dynnu'n ôl o'r astudiaeth unrhyw bryd hyd yn oed ar ôl llofnodi'r ffurflen gydsynio a hynny heb roi rheswm. Ni fydd eich penderfyniad i gymryd rhan neu dynnu'n ôl yn effeithio ar safon y gofal a gewch gan eich gwasanaethau gofal iechyd lleol.

Beth y gofynnir i mi ei wneud os penderfynaf gymryd rhan?

Os penderfynwch gymryd rhan bydd Emma yn cysylltu â chi ac yn eich gwahodd i gymryd rhan mewn cyfweiliad na fydd yn para mwy na 90 munud. Bydd Emma'n arwain y cyfweiliad ac yn ystod yr amser hwn bydd yn eich gwahodd i drafod amrywiaeth o bethau yn cynnwys: eich profiadau o newidiadau corfforol, sut y gwnaeth hyn wneud i chi deimlo, a wnaethoch siarad ag unrhyw un am y newidiadau hyn ac a wnaeth hynny ddylanwadu ar eich penderfyniad i fynd i weld y meddygon. Bydd y sgysiau yn ystod y cyfweiliadau yn anffurfiol ac mor ymlaciol â phosib. Cynhelir y cyfweiliadau ar gampws prifysgol Bangor (Wrecsam neu Fangor). Cynigir dewis o weithiau a dyddiadau.

A fydd fy nghyfraniad yn cael ei gadw'n gyfrinachol?

Bydd yr holl wybodaeth a gaiff ei rhannu yn y project yn cael ei chaw'n hollol gyfrinachol. Serch hynny, mae'n ofynnol yn ôl y gyfraith i'r tîm ymchwil dorri cyfrinachedd pan ddatgelir achosion o gamymddygiad neu risg o niwed i'r hunan neu eraill.

Caiff y trafodaethau yn ystod y cyfweiliad eu recordio ar dâp a'u hysgrifennu (trawsgrifio) ar ôl y sesiwn i alluogi'r ymchwilydd i ystyried y sgysiau. Ni fydd yn bosib adnabod eich sylwadau fel eich rhai chi o'r trawsgrifiadau, nac yn unrhyw adroddiad llafar neu ysgrifenedig dilynol am y cyfweiliadau. Bydd yr ymchwilydd yn defnyddio enw arall neu god pan fydd yn defnyddio gwybodaeth o'ch cyfweiliad (gall hyn fod ar ffurf dyfyniadau ysgrifenedig a gymerwyd o'r cyfweiliad ar gyfer cyflwyniadau, cynadleddau, mewn gwaith ysgrifenedig neu gyhoeddiadau). Ni fydd y recordiadau yn cael eu clywed gan unrhyw un heblaw am drawsgrifwyr ac ymchwilwyr Prifysgol Bangor. Bydd y recordiadau sain yn cael eu trosglwyddo i gyfrifiaduron a ddiogelir gan gyfrinair a cheir gwared arnynt yn unol â pholisi Prifysgol Bangor.

Fyddda i'n cael fy nhalu am gymryd rhan mewn cyfweiliad?

Mae'r cyfweiliadau'n wirfoddol ac ni fyddwch yn cael unrhyw daliad am gymryd rhan. Byddwn yn ad-dalu costau teithio rhesymol.

Beth yw anfanteision a risgiau posib cymryd rhan?

Nid ydym yn rhagweld unrhyw anfanteision na risgiau o ganlyniad i gymryd rhan yn y cyfweiliad hwn. Fodd bynnag, un anfantais bosib yw y bydd cymryd rhan yn gofyn am 90 munud o'ch amser ar y mwyaf. Nid yw cwestiynau'r cyfweiliad wedi'u llunio gyda'r bwriad o newid unrhyw agwedd ar eich ymddygiad; yn hytrach, mae'r cyfweiliad yn gobeithio cael dealltwriaeth ddofn mewn perthynas â'ch profiadau blaenorol. Fodd bynnag, pe bai unrhyw bryderon yn dod i'r amlwg yn y drafodaeth, byddwn yn eich annog i siarad amdanynt gyda'ch meddyg teulu neu ddarparu taflen wybodaeth am wasanaethau cefnogi perthnasol.

Beth yw manteision posib cymryd rhan?

Bydd cymryd rhan yn y cyfweiliad yn gyfle i chi fynegi eich barn a pham yr aethoch, neu nad aethoch, i weld y meddygon. Er nad oes unrhyw fanteision uniongyrchol i chi'n bersonol, gobeithir y bydd y wybodaeth a gafwyd a chanlyniadau'r project hwn yn ein helpu i ddeall pam fod rhai pobl yn ceisio gofal a chyngor meddygol proffesiynol a pham nad yw rhai pobl yn gwneud hynny. Gall hyn yn ei dro

arwain at ymchwil yn y dyfodol a chyfrannu at wybodaeth llunwyr polisi ynghylch syniadau pobl am geisio cyngor meddygol.

Beth os aiff rhywbeth o'i le?

Nid ydym yn rhagweld unrhyw amgylchiadau lle bydd cymryd rhan yn y cyfweiliad hwn yn gwneud niwed i chi. Fodd bynnag, os ydych yn dymuno cwyno am unrhyw agwedd ar y ffordd y cawsoch eich trin neu'n anhapus ynghylch unrhyw agwedd ar gymryd rhan yn y project, gofynnwn i chi roi gwybod i ni yn y lle cyntaf, fel y gallwn geisio datrys unrhyw bryderon a dod o hyd i ateb. Fel arall, dilynwch drefn gwyno Prifysgol Bangor os gwelwch yn dda.

Beth fydd yn digwydd ar ddiwedd yr project ymchwil?

Bydd canlyniadau'r astudiaeth yn cael eu cyhoeddi mewn cyfnodolyn gwyddonol a chânt eu cynnig ar gyfer eu cyflwyno mewn cyfarfodydd lleol a chenedlaethol perthnasol.

Pwy sydd wedi adolygu'r astudiaeth?

Mae'r project wedi cael ei adolygu a'i gymeradwyo gan Bwyllgor Moeseg Academaidd Gwyddorau Gofal Iechyd a Meddygol Prifysgol Bangor.

Beth ddylwn ei wneud os hoffwn gael rhagor o wybodaeth am y project?

I gael rhagor o wybodaeth am y project hwn, i gymryd rhan yn y project, neu os oes gennych unrhyw bryderon, cysylltwch â:

Emma Campbell

Canolfan Ymchwil Gofal Sylfaenol Gogledd Cymru
Prifysgol Bangor,
Cambrian 2,
Parc Technoleg Wrecsam,
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LL13 7YP.

Ffôn: 01248383515

E-bost: psp91a@bangor.ac.uk

Mae Emma Campbell yn gweithio dan oruchwyliaeth:

Dr Julia Hiscock j.hiscock@bangor.ac.uk

Dr Becki Law, Yr Athro Val Morrison a'r Athro Richard Neal.

Beth yw'r cam nesaf i mi?

Os dychwelwch y ffurflen ateb, bydd Emma'n cysylltu â chi yn ystod yr ychydig ddyddiau nesaf i drafod unrhyw gwestiynau sydd gennych, i gasglu gwybodaeth amdanoch ac i egluro beth fydd yn digwydd nesaf. Mae croeso hefyd i chi ffonio Emma i ofyn unrhyw gwestiynau pellach neu i fynegi eich

diddordeb mewn cymryd rhan. Os cytunwch i gymryd rhan yn y cyfweiliadau, gofynnir i chi lofnodi dau gopi o'r ffurflen gydsynio adeg y cyfweiliad. Cewch gopi o'r ffurflen gydsynio a'r daflen wybodaeth hon i'w cadw. Bydd y tîm ymchwil yn cadw'r copi arall o'r ffurflen gydsynio.

Diolch yn fawr am roi eich amser i ddarllen manylion y project hwn.

Os ydych eisiau cwyno cysylltwch â:

Yr Athro Christopher Burton
Ysgol Gwyddorau Gofal Iechyd
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Adnabod newidiadau yn y corff ac ymateb iddynt

Fersiwn: 3

Ffurflen ymateb

Os oes gennych ddiddordeb cymryd rhan mewn cyfweiliad, llenwch y manylion isod, llofnodi'r ffurflen a'i hanfon i'r cyfeiriad a ganlyn.

Emma Campbell

Canolfan Ymchwil Gofal Sylfaenol Gogledd Cymru
Prifysgol Bangor,
Cambrian 2,
Parc Technoleg Wrecsam,
Wrecsam,
LL13 7YP

Caiff eich manylion eu defnyddio yng nghyswllt cynnal cyfweiliadau i'r ymchwil hon yn unig a dim ond aelodau awdurdodedig y tîm ymchwil a gaiff eu gweld.

Enw: _____

Cyfeiriad: _____

Tref: _____

Cod post: _____

Rhif ffôn yn ystod y dydd: _____

Cyfeiriad e-bost: _____

Hoffwn i'r tîm ymchwil ym Mhrifysgol Bangor gysylltu â mi i roi mwy o fanylion imi ynglŷn â chyfweiliad unigol.

Llofnod _____ Dyddiad _____

Appendix E

(Qualitative interview participant consent form)

Recognising and responding to bodily changes

Version: 3

Participant consent form

Phase one interviews

Participant ID number:

Name of Chief Investigator: Miss Emma Campbell

| | | |
|---|--|--------------------|
| | | Please initial box |
| 1 | I confirm that I have read and understand the information sheet dated/....../...., for the above project and that I have had the opportunity to ask questions about the study. | |
| 2 | I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, to decline to offer any particular information requested by the researcher if I wish, and with no consequences. | |
| 3 | I understand that if I withdraw from the study the researchers will use the information I have provided up until that point, unless I indicate otherwise. If you do not want the team to use the information from the interviews then this data can be permanently deleted upon request. | |
| 4 | I agree to the interview being audio recorded. | |
| 5 | I agree to the use of anonymised quotes in presentations and publications. | |
| 6 | I understand that the research team is required by law to break confidentiality where cases of malpractice, abuse, or risk of harm to self or others are disclosed. | |

| | | |
|---|---|--|
| 7 | I understand that any information about my health that I share during the interview is not part of a medical consultation and that medical advice will not be offered. I agree to take part in the study. | |
|---|---|--|

Name of Participant

Date

Signature

Researcher obtaining consent

Date

Signature

Should you have any queries concerning this project, please contact:

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Cambrian 2

Wrexham Technology Park

Wrexham

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Tel: 01248383515

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Emma Campbell is working under the supervision of:

Dr Julia Hiscock j.hiscock@bangor.ac.uk

Dr Becki Law, Professor Val Morrison and Professor Richard Neal.



Appendix F

(Interview debrief)

CANOLFAN GOGLEDD CYMRU AR GYFER YMCHWIL GOFAL CYCHWYNNOL

NORTH WALES CENTRE FOR PRIMARY CARE RESEARCH



Recognising and responding to bodily changes

Debrief; version: 1

I would like to take this opportunity to thank you for taking the time to participate within this interview. Please could you take a moment to consider if there is anything about the interview that you would like to discuss with me?

One of the areas we were hoping to explore is how people respond to bodily changes or physical symptoms when they thought that they may indicate illness. For example, do people visit the doctors or a healthcare professional more quickly if they thought their bodily changes or symptoms might be cancer in comparison to asthma?

Please could I remind you that all of our interviews are confidential, that the transcripts will be anonymised and that you can withdraw at any point from this project.

If you feel that the interview has brought about any unforeseen issues and would like to talk about this further you could consider seeking advice from your local GP service.

Thank you for your time today, this project has been funded by Tenovus Cancer Care and we plan to use all of the findings to help improve our understanding about what influences people's decision to go to the doctors.

Kind regards,

Emma Campbell.

Knowledge Economy Skills Scholarships (KESS 2) is a pan-Wales higher level skills initiative led by Bangor University on behalf of the HE sector in Wales. It is part funded by the Welsh Government's European Social Fund (ESF) convergence programme for West Wales and the Valleys.



Appendix G*(Interview schedule)*

Interview Schedule

Bodily signs and changes

- Can you tell me what physical changes in your body you have been experiencing?
- In what way do you feel different from how you normally feel?

(How did you know you feel different/why or in what way?)

- What was it about these changes in your body that made you notice a difference?

(Was there something in particular? What made you aware? Different sensations? Did you notice these changes or someone else?)

Bodily signs and changes as potential illness symptoms

- How would you explain these changes to someone else who had no understanding about what you have been experiencing?

(Why would you describe the changes in that way? Is there anything else you would share to help them understand? Can you tell me a little more?)

- Have you ever experienced something similar to this before?

(How long ago was that? Is it the same for you now as last time or not? Same/ different? What happened previously?)

- Has anyone else you know shared any similar experiences to you?

(Was their experience the same/ different? In what way? What did they do or how did they react? Was this helpful for them or not?)

- Why do you think these changes have been happening?

(Has there been anything else which may have contributed to how you are feeling? In what way?)

- Has there been any other changes at all?

Emotional responses

- How do these bodily changes make you feel?

(What was it about the situation that made you feel concerned/or ok? Why was that do you think?)

- In what way have you responded to these feelings (For example, have you done anything about the way you feel or not?)

(Why did you do that/ did nothing? Did it change the way you feel about the situation in anyway? Was this helpful or not really?)

Lay referral

- Have you spoken to anyone else about these changes or gained any information?

(Who were they? Why did you speak with them? What did they think or say? Did they share any advice? Is what they said the same or different to what you were thinking? Did this offer you a chance to express how you were feeling? In What way was this helpful or not?)

- Would you speak with this person again or access information in this way again?

(Or is there something you would do differently? What might you expect if you did that?)

Appraisal

Did you think about gaining advice at all?

(Did you arrange to see a healthcare professional or not? What made you make that decision? Was it helpful to gain advice or not? Did you speak with anyone about your decision at all? What did they say about it?)

- Is there anything else that you would like to tell me about today?

Appendix H

(IPA analysis extract)

How does perfectionism, conscientiousness etc link ?? Personality??

So can you tell me about what physical changes that you've been experiencing over the last couple of months?

Well, yeah, it's been a few months now - September / October when I realised something wasn't right. Because (.) being that aware, like I said,

I'm quite a perfectionist; I really want to do things the proper way, you know, and if I don't know I'll ask. You have to be accountable for what you do. And I said that one morning, went to work, and I could feel something not right with me, I couldn't focus, I couldn't -. Whatever I read, it didn't go in. I was trying to do my job. I started feeling achy and could hard - could hardly walk. And something (.) like a tsunami came all over me. I felt like, "Hang on, this doesn't feel right." I was -. It was like a

Is this an expression of Conscientiousness ?? Or anxiousness??

Retrospective adaptive perfectionism and the disrupted perfectionist (perceptual recognition)

Perceptual recognition, the disruption, activity and self

Perseus self adaptive perfectionist

Duration of experience - a few months

View of self 'perfectionist'

Retrospective recognition of bodily changes; at work

Emphasis upon her own experience

Recognition, disruption of self at work in the work context

Use of metaphor

How Marie views herself

How does this link to why is Marie's confidence lead to a negative view of herself?

little build-up the day before. I started getting quite (.) or (.) my

Perfectionism becomes maladaptive through her bodily changes?

confidence had been away from me and thinking the worst of me and

self questioning or experience

saying, "Oh, I don't feel right but why?" You know, and you feel tired all the time. You just come on you. And even your - As if you've got no

more logic left in you. You can't think straight. And I thought, "This is not right." But it worried me because I was working as well. I didn't wanna

Emotion nature of experience - effect on work and increased negative affect

Emphasis upon herself in the wider work context

make mistakes and I felt embarrassed in the same time so I think I put

Influence upon that Marie herself has upon it when more pressure and my body was one big ache. Or even getting off my

Distraction to the experience of one's own body

'Perfectionism becomes maladaptive through illness experience'

desk, even that, I could hardly walk away from it 'cause I felt really achy,

widespread pain all over. That was my first sign. So I had to go and see

my manager, my acting manager at the time because our manager left.

Discusses with manager

Conscientiousness in reference to her work place responsibilities, is her negative affect increase when a disruption to this takes place. How does Marie self-regulation through this 'conscientiousness' / Sense of responsibility?

The disrupted maladaptive perfectionist and anxiety

Interconnected physical & negative emotional experience

Recognition through the disruption of work

Recognition beyond relational factors

Confidence - the feeling or belief that one can have faith in or rely on someone

loss of faith in herself??

Ambiguous bodily changes - multiple bodily changes - psychological impact upon oneself?

Intrinsically self-critical

64 Importance of her manager knowing her previously as a companion to her current self/strate?

65 for a few weeks and then I said, "Look, I don't think I'm right. I don't feel

66 right." She said, "Actually," she said, "I can tell." She said, "I can see in

67 your eyes." (.) And I thought, "Pardon?" Said, "What?" And she said,

68 "Whatever you do," she said, "I know you can do your job otherwise I

69 wouldn't have employed you." I think she tried to build my confidence.

70 And I knew that something wasn't me who was in that body, it was

71 someone else, because I could see the changes like that in split second.

72 I still didn't figure out why. Do you know what I mean? And that's when

73 she said, "You need to go home and don't come back till you're ready, till

74 you're right, 'cause otherwise it's not gonna help you in the slightest

75 Or is this some form of awareness, Marie wanting to port herself in a certain way? Or is the awareness now due to her illness experiential + trauma

76 coming back to work you know and feel the strain again and the tension."

77 Um (.) so I went to see the doctor and he's been signing me off from

78 month to month because I still get very (.) or sudden fatigue, I-I get

79 aches, very different symptoms to physical pain. Er my joints, I get um (.)

80 they don't flex properly and you feel like you're gonna fall. Um (.) what

81 else? How I feel? Tingling everywhere, or like you've got sunburn all

82 over. It's weird. Very strange. And, to be honest, I had er filled up a

83 questionnaire the doctor gave me and there was a lot of symptoms that's

84 listed and I almost listed all of them because I thought, "This is not in my

85 mind. I know I can feel it." It's very difficult to-to think, "Am I imagining it

or is it happening to me?" But I-I know that even if I was ill I could still go

Why would Marie think it's all in her mind?

Hightened negative affect

Does Marie experience increased NA due to her 'consciousness'?? + the internal unpredictability??

Adaptive consciousness + perception; the previous self through the narrative of others

A dissociated sense of self

Validation current experience or her sense of self

External observation of experience from manager

As 'consciousness' both Marie + her manager could 'see' the changes

Her experience some has been detached?

How do these changes make her the physical self when Marie makes reference to as 'someone else'?

Or is this some form of awareness, Marie wanting to port herself in a certain way? Or is the awareness now due to her illness experiential + trauma

75 coming back to work you know and feel the strain again and the tension."

76 Um (.) so I went to see the doctor and he's been signing me off from

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85 or is it happening to me?" But I-I know that even if I was ill I could still go

Why would Marie think it's all in her mind?

Hightened negative affect

Does Marie experience increased NA due to her 'consciousness'?? + the internal unpredictability??

Consuming behaviour

Painful thinking

arguing experience

Fatigue as a bodily change

Fatigue not about joint movement

Tingling

Sensory experience

Validation of her experience

Connection related to her own experience

Physical Vs Psychological

Anxious due to lack of physical/diagnostic signs to be reliable not work

No being able to be reliable not work

Increased NA due to the internal unpredictability??

Ambiguous + inconsistent bodily changes

Or the altered sensory experience

Invisibility, anxious experiential self - doubt

The dramatic maladaptive perfectionist and anxiety

86 Different from other illness experience? *Immersion??*
 to work but this has stopped me from going to work. Do you know what I mean? *Researcher agrees / understands her position?*

87 Highlighting severity of the experience
 mean? If it was a different type - a cold or something. But I knew I *Self*
importance grounded in her

88 Psychological / physical impact *enough*
 couldn't function and that is worrying still to me now because I wanna go *The emotional impact*
Consequences of her experience + the emotional nature of assumption

89 Due to bodily changes the perfectionist became *maladaptive*
 back to my job. Do you know what I mean? And I-I really was very um *NA?*
 Dukkha??

90 (.) looking forward to this job, purely because my last job ended up quite *Premises difficulties at work*

91 in a bad way. I was bullied. And this is probably a knock-on effect as well

92 Repeated experiences
 as - on top of my other trauma. And maybe my body said, "Hang on, no *physical bodily change*
'trauma' induced??

93 more." And this is why I know something has to - my body is not like it *Self Compensation*
The body communicates dejection

94 was. I know I'm getting older but come on, I don't feel like even if I have a

95 good night's sleep I don't feel like I had one. Even now, I get, while

96 Emphasis upon reality of her experience?
 speaking to you, I get tingling pain and er burning pain and it's like *Current experiences & the interview*

Is there some form of bodily dejection?? Separation, it's her body
'Saying hang on...' No threat to a sense of self??

Immersion, the experience of immersion; illness experiences and the present self

97 Frequency of experience
second nature. I know they're there, but they wear you out. Do you know

98 Emphasis
what I mean? My back, especially. Because I went -. Because I thought

99 my backache was nothing to do with what I've got and I had lower

100 Self-help
backpain and I thought I'll go to the chiropractors just to eliminate some

101 of the discomfort that I've got, you know, 'cause I knew I wasn't right. It

102 flared it up even more when I went three times. I paid private and I

103 couldn't go back. I could hardly walk.

104 R: So you went three times?

105 Marie: Yeah, and I stopped going. So I'm waiting to go and see the physio and

106 because I have been seeing the consultant there and this is his physio.

9 The effect of the bodily changes, self as no longer working in the way Marie once did?

Marie suggesting that the researcher understands or agrees with her experience.

Private -
Previous ineffective / negative help-seeking.
↓
Withdrawal from previous engagement
Creates delay

Intellectual Self-help / treatment

Delay need?

Referral to physio - fellow HCP consultation

Previous ineffective and negative experiences or healthcare services

107 Respective bewildered + medically unexplained symptoms

108 Previous condition - under consultant

109 They know 'cause I've got degenerative disc and I have the injection. But

110 many sense - pain

111 it's-it's gonna -. It's more about my back. Um (.) but I think it's all

112 connected with whatever the trauma it's caused me because they don't

113 like labelling it, the doctors, the symptoms, my diagnosis, because it's

114 very difficult because it could be so many different things causing it and

115 Why does the diagnostic label matter for Marie??

116 these are quite common symptoms but yet it cross over other (.)

117 Indicating the researcher knows or understands diseases / illnesses, you know? But he did say it looks like it's FMS:

118 fibromyalgia. (.) I think fibromyalgia -. But then the doctor, the

119 what is it about experiencing fibromyalgia that moderates her occupational -. he doesn't think it is, so I'm a bit confused. Purely understanding?

120 Is it because it physical symptoms

121 because, he said, "The trauma that you've been through, I am surprised

122 you haven't gone off sick sooner than this." I said, "Ah?" I said, "Come

123 HCP highlighting the influence of her traumatic experiences

124 As it hasn't actually been explained how trauma can cause physical bodily changes? Is the medical mechanism important for her experience?

125 Has Marie's interpretation shaped through life events and ambiguous medical understanding

126 Marie's interpretation + causation or experience

127 Impact of external factors which Marie has found traumatic, situational factors → causing distress → distress causing bodily changes??

128 Ambiguous understanding diagnosis from HCP

129 Differing professional advice

130 Her own experienced knowledge - life events - multiple consultations with different medical

131 physical symptoms generally fall within medical diagnostics?? Does Marie not feel like a patient with a diagnosis or Does the lack create negative affect?

Appendix I

(The Experiences in Close Relationships Scale)

Experiences in Close Relationships (Brennan, Clark, & Shaver, 1998)

Instructions: The following statements concern how you feel in romantic relationships. We are interested in how you generally experience relationships, not just in what is happening in a current relationship. Respond to each statement by indicating how much you agree or disagree with it. Write the number in the space provided, using the following rating scale:

| | | | | | | | | |
|-------------------|---|---|---|---------------|---|---|--|----------------|
| Disagree Strongly | | | | Neutral/Mixed | | | | Agree Strongly |
| 1 | 2 | 3 | 4 | 5 | 6 | 7 | | |

- ___ 1. I prefer not to show a partner how I feel deep down.
- ___ 2. I worry about being abandoned.
- ___ 3. I am very comfortable being close to romantic partners.
- ___ 4. I worry a lot about my relationships.
- ___ 5. Just when my partner starts to get close to me I find myself pulling away.
- ___ 6. I worry that romantic partners won't care about me as much as I care about them.
- ___ 7. I get uncomfortable when a romantic partner wants to be very close.
- ___ 8. I worry a fair amount about losing my partner.
- ___ 9. I don't feel comfortable opening up to romantic partners.
- ___ 10. I often wish that my partner's feelings for me were as strong as my feelings for him/her.
- ___ 11. I want to get close to my partner, but I keep pulling back.
- ___ 12. I often want to merge completely with romantic partners, and this sometimes scares them away.
- ___ 13. I am nervous when partners get too close to me.
- ___ 14. I worry about being alone.
- ___ 15. I feel comfortable sharing my private thoughts and feelings with my partner.
- ___ 16. My desire to be very close sometimes scares people away.
- ___ 17. I try to avoid getting too close to my partner.
- ___ 18. I need a lot of reassurance that I am loved by my partner.
- ___ 19. I find it relatively easy to get close to my partner.
- ___ 20. Sometimes I feel that I force my partners to show more feeling, more commitment.
- ___ 21. I find it difficult to allow myself to depend on romantic partners.

Disagree Strongly Neutral/Mixed Agree Strongly
 1 2 3 4 5 6 7

- ___ 22. I do not often worry about being abandoned.
- ___ 23. I prefer not to be too close to romantic partners.
- ___ 24. If I can't get my partner to show interest in me, I get upset or angry.
- ___ 25. I tell my partner just about everything.
- ___ 26. I find that my partner(s) don't want to get as close as I would like.
- ___ 27. I usually discuss my problems and concerns with my partner.
- ___ 28. When I'm not involved in a relationship, I feel somewhat anxious and insecure.
- ___ 29. I feel comfortable depending on romantic partners.
- ___ 30. I get frustrated when my partner is not around as much as I would like.
- ___ 31. I don't mind asking romantic partners for comfort, advice, or help.
- ___ 32. I get frustrated if romantic partners are not available when I need them.
- ___ 33. It helps to turn to my romantic partner in times of need.
- ___ 34. When romantic partners disapprove of me, I feel really bad about myself.
- ___ 35. I turn to my partner for many things, including comfort and reassurance.
- ___ 36. I resent it when my partner spends time away from me.

Appendix J

(The Brief Illness Perception Questionnaire)

The Brief Illness Perception Questionnaire

For the following questions, please circle the number that best corresponds to your views:

| |
|--|
| How much does your illness affect your life? <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 5px;"> <div style="text-align: center;">0 no affect at all</div> <div>1 2 3 4 5 6 7 8 9</div> <div style="text-align: center;">10 severely affects my life</div> </div> |
| How long do you think your illness will continue? <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 5px;"> <div style="text-align: center;">0 a very short time</div> <div>1 2 3 4 5 6 7 8 9</div> <div style="text-align: center;">10 forever</div> </div> |
| How much control do you feel you have over your illness? <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 5px;"> <div style="text-align: center;">0 absolutely no control</div> <div>1 2 3 4 5 6 7 8 9</div> <div style="text-align: center;">10 extreme amount of control</div> </div> |
| How much do you think your treatment can help your illness? <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 5px;"> <div style="text-align: center;">0 not at all</div> <div>1 2 3 4 5 6 7 8 9</div> <div style="text-align: center;">10 extremely helpful</div> </div> |
| How much do you experience symptoms from your illness? <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 5px;"> <div style="text-align: center;">0 no symptoms at all</div> <div>1 2 3 4 5 6 7 8 9</div> <div style="text-align: center;">10 many severe symptoms</div> </div> |
| How concerned are you about your illness? <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 5px;"> <div style="text-align: center;">0 not at all concerned</div> <div>1 2 3 4 5 6 7 8 9</div> <div style="text-align: center;">10 extremely concerned</div> </div> |
| How well do you feel you understand your illness? <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 5px;"> <div style="text-align: center;">0 don't understand at all</div> <div>1 2 3 4 5 6 7 8 9</div> <div style="text-align: center;">10 understand very clearly</div> </div> |
| How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?) <div style="display: flex; justify-content: space-between; align-items: center; margin-top: 5px;"> <div style="text-align: center;">0 not at all affected emotionally</div> <div>1 2 3 4 5 6 7 8 9</div> <div style="text-align: center;">10 extremely affected emotionally</div> </div> |
| Please list in rank-order the three most important factors that you believe caused <u>your illness</u>. The most important causes for me:- <div style="margin-top: 10px;"> 1. _____ 2. _____ 3. _____ </div> |

Appendix K
(The Lay Referral Measure)

Lay referral measure

Part one: demographic characteristics of respondents

| | |
|--|---|
| Gender | <ul style="list-style-type: none"> • Female • Male • Other please specify • Prefer not to say |
| Life stage | <ul style="list-style-type: none"> • Later adolescence (18- 25 years) • Early adulthood (25- 40 years) • Middle adulthood (40- 65 years) • Older adulthood (65- 80 years) • Late adulthood (80 years and over) |
| Marital status | <ul style="list-style-type: none"> • Single (never married) • Married, or domestic partnership • Widowed • Divorced • Separated |
| Household composition Do you have a partner? Do you have children under the age of 18 years? Do your children live in your home? | <ul style="list-style-type: none"> • Yes • No <ul style="list-style-type: none"> • Yes • No <ul style="list-style-type: none"> • Yes, [number] that live in my house • No |
| Education What is the highest level of school you have completed or the highest degree you have received? | <ul style="list-style-type: none"> • Less than high school • High school or equivalent • Some college but no degree • Bachelor degree • Post graduate degree |

| | |
|---|----------------------------------|
| Predisposing conditions Do you experience any existing illnesses or disabilities? | Please specify |
|---|----------------------------------|

Part two: lay referral characteristics

| | |
|---|---|
| Lay referral Did you speak with anyone about your bodily changes or illness symptoms? | Yes No |
| Lay referral and network size: If so how many people? | 0 1 2 3 4 5 6 7 + |
| Lay referral composition by relationship Which of the following reflects the person or people you speak to? (Tick as many as relevant) | <ul style="list-style-type: none"> • Spouse • Sibling • Family member • Friend • Other (please specify who) |
| Lay referral Gender of the person you mainly speak with about your bodily changes or illness symptoms? | <ul style="list-style-type: none"> • Female • Male • Other • Prefer not to say |
| Length of relationship (years) Please could you indicate the duration of your relationship with the person you mainly speak with about your bodily changes or illness symptoms? | <ul style="list-style-type: none"> • 0-1 years • 1-5 years • 5-10 years • 10-15 years • 15 years + |

| | |
|--|--|
| Reason for lay referral Was there a particular reason you mainly spoke to this person? | Please specify |
| Direction of lay referral Did the other person suggest you seek healthcare professional a) Ever? b) For the last occasion of discussing your bodily changes or illness symptoms? | <ul style="list-style-type: none"> • Yes • No <ul style="list-style-type: none"> • Yes • No |
| Help-seeking behaviour Did you make an appointment to see a healthcare professional/ your GP? | <ul style="list-style-type: none"> • Yes • No |

Appendix L

(Online study advertisement)

Have you, or someone you know, recently experienced any bodily changes or illness symptoms?



Emma aims to explore how the quality of people's adult relationships influences their perception of illness, whom people talk to (or not) about their health experiences, and if this affects people's decision to gain healthcare professional advice.



Appendix M

(The mixed and multi methods participant information sheet)



Participant information sheet (V 1.2)

Lay referral: the influence of adult relationships in illness and health

If you have been experiencing any bodily changes or illness symptoms in the last three months, we would like to invite you to take part in this Tenovus funded research project. These bodily changes or illness symptoms may include: headaches, pain, bleeding, weight loss, lumps, tiredness, nausea, chest problems, abdominal issues, or any other physical changes you have noticed. Before you can decide whether or not to take part in our study; you will need some information about what this project involves. Please take the time to carefully read the information below and discuss it with others if you wish. If there is anything that is not clear or if you would like some more information, please contact Emma using the details below.

What is the purpose of this study?

We are carrying out this online research study across Wales and England to explore how people's adult relationships influence whether they speak to someone about their bodily changes or illness symptoms, and if so, who they speak with. We are also interested in whether these adult relationships and the people spoken to affect people's decision to seek professional healthcare advice or not.

What the study involves

The study involves two different parts: part one invites you to complete a brief online survey which addresses these topics:

- Your experience of adult close relationships
- Your perceptions of illness
- Information about yourself and your life
- Who you might speak to about any bodily changes or illness symptoms

The second part of the study invites you to write a brief story about a topic provided by the researcher. This is also guided by a visual picture (pictures were sourced online through Google Images). The topics of the stories are:

- Your experience of talking to people (or not) about your bodily changes or illness symptoms during the COVID-19 pandemic
- Two hypothetical scenarios about a story character and who you imagine they spoke to (or not) about their bodily changes or illness symptoms.

Do I have to take part?

Participation in this online study is completely voluntary.

What will happen if I decide to take part?

If you decide to take part you will be asked to confirm you have read the participant information and online consent form before starting the study. Once you have completed the online consent form, you can then start the online survey. However, you are still free to withdraw from the study at any time without giving a reason (although feedback is welcome). The study will take approximately an hour depending upon the length of your written stories. The study itself will be conducted in English although a brief summary of the findings can be made available in Welsh at the end of this study. If you would like to gain a summary of the findings, please express an interest when you complete the online consent form.

Will my answers to the questionnaires and stories be kept confidential?

All information collected as part of this study will be kept confidential. Only members of the research team will have direct access to the information you provide and your name, any identifying details will not be included in our study reports, presentations, or publications. The data and information collected will be securely stored following Bangor University and national Data Protection policy. Only in exceptional cases when the information given suggests that yourself or another person is at serious risk (of severe personal distress,

abuse, malpractice), the researcher may share this information with other relevant professionals.

Are there any possible disadvantages, advantages, or benefits if I take part?

The information you provide in this online study will help us to understand how people's quality of adult relationships influences who (or if) they talk to other people or gain healthcare professional advice when they experience bodily changes or illness symptoms.

The overall study will be useful to help us to consider future research and the development of health interventions.

You will not be paid for your time or participation. Whilst there may be no direct benefits to you, there are potential long-term benefits to others. At this stage there are no known disadvantages or risks associated with taking part in the study, other than that we ask for some of your time. In the unlikely event that the study causes you distress at the time of taking part, please feel that you can take a break before deciding whether or not to continue or to omit some answers. If the topics raise any later questions for you, you can also contact a member of your healthcare team, your GP or local helplines, for support.

What will happen to the results of this study?

The results will be written up for publication in health-related academic and practitioner journals and will likely also be presented at local, national, and international conferences including that of Tenovus.

Who is organising this study?

This study is being carried out by Emma Campbell at Bangor University as part of her Ph.D. research. Emma's Ph.D. is funded as part of the Knowledge Economy Skills Partnership 2 (KESS 2) program and is in partnership with Tenovus Cancer Care. Annalise Kerry, Beth Getu, and Erin Jones are other named researchers and the project is supervised by Professor Val Morrison and Dr. Jaci Huws at Bangor University.

Who can I contact for further information?

For more information about this research, please contact:

Emma Campbell via email on psp91a@bangor.ac.uk

Who has reviewed the study?

This project was reviewed and approved by the Healthcare and Medical Sciences Academic Ethics Committee at Bangor University.

For complaints please contact:

Dr Lynne Williams, Head of the Health Science School, Bangor University.

Direct line: 01248 383170

Email: lynne.williams@bangor.ac.uk

Thank you for taking the time to read this Information Sheet.

If you would like to take part in this study please proceed to the online consent section.



Appendix N

(The mixed and multi methods consent form)

Online consent form (V 1.2)



Lay referral: the influence of adult relationships in illness and health

I have read and understood the online *Participant Information* and I understand that I have the right to withdraw from the research at any point. I also understand that my rights to anonymity and confidentiality will be respected.

A digital copy of my agreement to consent to take part in this study will be electronically collected as part of the online data collection process by Emma and the team.

I understand that I can print or save a PDF copy of my answers once I have completed the questions which includes my consent to take part in this study.

I confirm that:

- I have read and understood the *Participant Information*. I agree to take part in this study and I have had the opportunity to consider the information and speak with other people
- I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected
- I agree to my personal data and other data I provide during this study being processed as described in the Participant Information Sheet
- I understand that if during the study I tell the research team something that causes them to have significant concerns about my health and/or welfare they may need to breach my confidentiality
- I agree to my data being anonymised in the production and publication of study reports or in the use of written quotes from my stories within these
- I would like to receive a summary of the online study findings in English Yes/ No
- I would like to receive a summary of the online study findings in Welsh Yes/ No

Participants' details

- Name
- Email address
- Phone number



Appendix O

(*A priori* set of themes)

A priori of themes

| Adult attachment style and placeholder codes | Specific adult attachment style a priori themes |
|--|--|
| Secure template | <ul style="list-style-type: none"> • Positive view of self in the context of lay referral • Positive view of other in the context of lay referral • Positive view of self in the context of healthcare consultation • Positive view of other in the context of healthcare consultation |
| Preoccupied template | <ul style="list-style-type: none"> • Negative view of self in the context of lay referral • Positive view of other in the context of lay referral • Negative view of self in the context of healthcare consultation • Positive view of other in the context of healthcare consultation |
| Dismissing template | <ul style="list-style-type: none"> • Positive view of self in the context of lay referral • Negative view of other in the context of lay referral • Positive view of self in the context of healthcare consultation • Negative view of other in the context of healthcare consultation |
| Fearful avoidant template | <ul style="list-style-type: none"> • Negative view of self in the context of lay referral • Negative view of other in the context of lay referral • Negative view of self in the context of healthcare consultation • Negative view of other in the context of healthcare consultation |

Appendix P

(Templates as part of the template analysis)

COVID

Template one

| Adult attachment style and placeholder codes | Specific adult attachment style a priori themes and template one |
|--|---|
| Secure | <ul style="list-style-type: none"> • Positive view and active self in the context of lay referral • Positive view of other in the context of lay referral • Positive and active view of self in the context of healthcare consultation • Negative view of other and decreased of healthcare consultation (Changed) |
| Preoccupied | <ul style="list-style-type: none"> • Positive view of other in the context of lay referral (Some removed) • Negative view of other in the context of lay referral (Added) • Negative view of healthcare services (Changed) |
| Dismissing | <ul style="list-style-type: none"> • Positive and active view of self in the context of lay referral • Negative view of other and decreased lay referral • Positive and active view of self in the context of healthcare consultation • Negative view of other and decreased of healthcare consultation |
| Fearful avoidant | <ul style="list-style-type: none"> • Negative view of self and decreased lay referral • Negative view of other and decreased lay referral • Fearful for others and increased lay referral (Added) • Negative view of self and decreased healthcare consultation • Negative view of other and decreased of healthcare consultation |

COVID

Template two

| Adult attachment style and placeholder codes | Template two |
|--|--|
| Secure template (Part as expected and re-developed) | <p>Reciprocal and responsive lay referral</p> <ul style="list-style-type: none"> Positively views the self as actively engaging with lay (Abductive theme which aligns with AT style) <i>*Positively, as in there was a repeated emphasis on the engagement with lay referral in the group.</i> Positively views self as responsive to others; lay referral (Additional and an abductive theme found in the data regards to AT) <i>*Creating support for others, protective of others' emotions.</i> Positively views others as responsive; lay referral (Abductive theme which aligns with AT style) <i>*Trust in others, seeking/ sought reassurance, comfort, validation of experience.</i> <p>Differing perspectives and access to healthcare services</p> <ul style="list-style-type: none"> Positively views the self as actively accessing healthcare services (Abductive theme which aligns with AT) <i>*Positively in terms of the focus being upon engagement with and access to services during COVID</i> Negative perceptions of healthcare services, a decrease and perceived COVID barriers (Positive 'other' has been removed as was not found in the data and this theme is an additional theme. Is this theme a reflection of the pandemic and if so, how does this relate to the deactivation of attachment systems for some in this group based upon their perception of HCP services being under stress etc.? Is it a decrease to deactivation of motivation?) <i>*Avoid placing stress on the system, services under pressure/stress, system challenges.</i> |

| | |
|---|---|
| <p>Preoccupied template (Part as expected and re-developed)</p> | <ul style="list-style-type: none"> • Negative view of self in the context of lay referral (removed not enough evidence in the data) <p>Differing perspectives and engagement with lay referral</p> <ul style="list-style-type: none"> • Positively views others as responsive; lay referral <p>(Abductive theme which aligns with AT style)</p> <p><i>*Trusts, gains options, emotional regulation</i></p> <ul style="list-style-type: none"> • Negative view of others, avoidant lay referral and fearful COVID anticipated consequences?? <p>(Additional theme/ abductive- How does this relate to deactivation during COVID based upon the participant's projected negative perceptions of others response in response to potential COVID symptoms?) This was later changed in template three, and reviewed in terms of the self and other and re-order.</p> <p><i>*Others judgements, assumptions/ thoughts re-COVID, worry, paranoia</i></p> <ul style="list-style-type: none"> • Negative view of healthcare services, a decrease and perceived COVID barriers <p>(Positive 'other' has been removed as was not found in the data and this theme is an additional theme. Is this theme a reflection of the pandemic and if so how does this relate to the deactivation of attachment systems for some in this group based upon their perception of HCP services being under stress etc.? Secure & Pre-same in terms of this?)</p> <p><i>*System challenges/ discussing Issues, risk of infection etc.</i></p> <ul style="list-style-type: none"> • Negative view of self in the context of healthcare consultation (not enough evidence in the data- removed) • Positive view of other in the context of healthcare consultation (not enough evidence in the data) |
| <p>Dismissing</p> | <p>A majority of engagement; lay referral</p> <ul style="list-style-type: none"> • Positively views the self as actively engaging with lay referral |

| | |
|---|--|
| (As expected and developed) | <p>(Abductive theme which aligns with AT style)</p> <p><i>*Positively, as in there was a repeated emphasis on the engagement of lay referral in this group, some disclosed that there has been no changes because of COVID and that they continue to engage with lay referral, were others discussed 'duty of care', openness and their honesty.</i></p> <ul style="list-style-type: none"> • Negative view of others and decreased COVID lay referral <p>(Abductive theme which aligns with AT style)</p> <p><i>*Some participants reported a decrease of lay referral due to other people worries, cautions and judgments.</i></p> <p>Differing perspectives and access to healthcare services</p> <ul style="list-style-type: none"> • Positively views the self as actively accessing healthcare services <p>(Abductive theme which aligns with AT style)</p> <p><i>*Positively in terms of the focus being upon access to services during COVID. Participants discussed accessing services when they needed to for existing conditions, and that they were more inclined to discuss covid symptoms with HPC's.</i></p> <ul style="list-style-type: none"> • Negative view of healthcare services, a decrease and perceived COVID barriers <p>(Abductive theme which aligns with AT style)</p> <p><i>*Participants discussed that there might be more important patients/ risk of infection if they were to go to the healthcare centre etc. This meaning for some they were less inclined to seek advice during COVID or experienced challenges.</i></p> |
| <p>Fearful avoidant</p> <p>(As expected and developed)</p> | <p>Decreased and avoidant lay referral</p> <ul style="list-style-type: none"> • Negative view of the interpersonal self <p>(Abductive theme which aligns with AT style)</p> <p><i>*Participants wrote about avoiding lay referral due to worries/ their negative perceptions round their ability to express symptoms/ worry and panic for others/ that their experiences were insignificant in the context of the COVID-19 pandemic.</i></p> |

| | |
|--|--|
| | <ul style="list-style-type: none"> Negative view of others, decreased lay referral and fearful COVID anticipated consequences <p>(Abductive theme which aligns with AT style)</p> <p><i>*Participants wrote about their negative views of lay referral and how others may make assumptions that they may have covid if they spoke about their experiences/ that it may cause unnecessary worry/ that other people may expect them to self-isolate= hence why lay referral decreased and became avoided.</i></p> <p>COVID-19 related fear for others, increased lay referral and help-seeking</p> <p>(Additional and an abductive theme found in the data regards to AT. Does this relate to AT, relationship anxiety?)</p> <p><i>*increase due to others being high risk, lay referral as a way to put people's mind at rest and for the protection/ or as a precaution for others.</i></p> <p>Decreased and avoidance of healthcare consultation</p> <ul style="list-style-type: none"> Negative view of self as a healthcare service user <p>(Abductive theme which aligns with AT style)</p> <p><i>*Not important enough during covid, taking something they shouldn't, wasting the doctors time.</i></p> <ul style="list-style-type: none"> Negative view of healthcare services, a decrease and perceived COVID barriers <p>(Abductive theme which aligns with AT style)</p> <p><i>*Services too busy, decreased engagement/ not comfortable with new online services, system challenges, risk of infection.</i></p> |
|--|--|

Template Three

| Adult attachment style and placeholder codes | Template three |
|--|--|
| Secure | <p>Responsive and reciprocal lay referral</p> <ul style="list-style-type: none"> Positively views the self as typically actively engaging with, or increased lay referral with close others Positively views others as responsive; regulatory lay referral and making sense Positively views self as responsive to others needs in a pandemic; lay referral <p>Active engagement and COVID related disengagement with healthcare services</p> <ul style="list-style-type: none"> Positively views the self as actively adjusting and accessing healthcare services Altered negative perceptions of healthcare services, cautious and decreased access |
| Preoccupied | <p>Divergent self and other perceptions; the experience of lay referral</p> <ul style="list-style-type: none"> Negative anticipated consequences for the self; decreased and avoidant lay referral Positively views others as responsive; affect regulation, lay referral and making sense <p>Altered negative perceptions of healthcare services, cautious and decreased access</p> |
| Dismissing | <p>Typical lay referral engagement and relational affect disengagement</p> <ul style="list-style-type: none"> Positively views the self as actively engaging with lay referral Decreased lay referral; negative view of others and relational affect <p>Active engagement and COVID related disengagement with healthcare services</p> <ul style="list-style-type: none"> Positively views the self as actively accessing healthcare services |

| | |
|------------------|--|
| | <ul style="list-style-type: none"> Negative perceptions of healthcare services, cautious and decreased access |
| Fearful avoidant | <p>Decreased fearful avoidance of lay referral</p> <ul style="list-style-type: none"> Lay referral; negative view of the interpersonal self Negative view of others, decreased lay referral, fear of isolation and separation Health related fear for others, hypervigilance, and help-seeking <p>Decreased and avoidance of healthcare consultation</p> <ul style="list-style-type: none"> Negative view of self as a healthcare service user Negative view of healthcare services, and decreased access |

Appendix Q

(Template analysis extract)

SC1-COVID

SC1 COVID DATA

1

2 Fearful avoidant (SC1-N=30)

3 P3-FA-SC1

4 I spoke to both of my grown-up children. I wouldn't normally, it's

5 been an 'open conversation' I'm usually much more private and

6 would only speak to my husband.

7 P9-FA-SC1

8 I was less likely to talk about any changes because I was worried

9 about not knowing how to describe them. I did not gain any

10 professional advice as I found the phone triage system challenging

11 for local GP. Spoke in general terms of feeling unwell with close

12 family but provided no details. Felt less able to talk about it

13 because I was concerned people would assume, I had covid and

14 would just tell me to self-isolate.

15 P10-FA-SC1

16 I have spoken less about illness symptoms or changes to

17 friends/family in light of the current pandemic. I think out of fear of

18 having covid 19, and denial of anything that may be construed as

19 related. For example, having headaches for a few days, when

20 spoke about with family they all started searching online to find any

21 links between covid and headaches - and then creating worry that I

22 then have covid 19. Pretty much any symptom of illness has been

23 linked somewhat to covid - even if it's 1 case and could be

24 completely unrelated but just happened to be experienced at the

Negative view of the
interpersonal selfNegative view of
interpersonal self
& fearful
anticipated
consequencesNegative view of
services
Avoidant
concerned
worriedNegative view of
self + anticipated
consequences
fear
denialChanges in lay referral due to covid increased
Changes - lay referrallay referral
counsel Avoidant lay referralNegative view of
self - not
knowing
how to
describe
changes - decreased
changes - lay referral
counsel
express in
HCP?

Negative view of healthcare services - others

Negative perception of
self + social
avoidance
Negative perceptions of
others leading to
Self-isolationlay referral
counsel decreased
lay referralOthers may
construct as racist

Negative view of lay referral 'others'

Negative view of
other - HCP
= Services
- System +
- doctors
- GPs

SC1-COVID

- 25 same time as covid. So, any symptom could theoretically be linked
- 26 to covid by friends/family, no matter how ridiculous - so it's easier
- 27 to avoid talking about it.
- 28 P11-FA-SC1
- 29 living alone and being in lockdown during the last few months I
- 30 haven't really spoken to anyone about changes to my health. I do
- 31 still have some contact with people in work and I have spoken a
- 32 little about changes to my level of activity. I injured my knee just
- 33 before lockdown and was seeking treatment from a physical
- 34 therapist, which has been postponed during the lockdown. Not only
- 35 have I lost the day-to-day activity of my working life, exercise has
- 36 been difficult. Mostly this affected my mood states, getting quite
- 37 depressed in the first month. I have been able to improve this by
- 38 introducing exercise which does not make things worse, attempting
- 39 to remove self-imposed pressures concerning myself being an
- 40 exerciser. However, there are other health issues which are minor,
- 41 they may be of some concern, but I don't feel warrants seeing a
- 42 doctor. My biggest concern is not being as active as I'm used to.
- 43 P12-FA-SC1
- 44 I am less likely to admit symptoms to my family which are similar to
- 45 those of covid, e.g., coughs, feeling abnormally warm. this may be
- 46 because my parents are older and I do not want to worry them.
- 47 However, I am more comfortable telling friends. I would be less
- 48 likely to call a healthcare professional if I displayed flu symptoms

Negative view of others
lay referral

Avoidance
decreased
lay referral

No lay referral

Negative Mood

Negative view of Self

No HCP advice

Avoidant

Can't lay referral

decreased
lay referral

Negative view of
Self & Lay

Decreased/avoidant
HCP

Reluctance

Creating
Worry

Negative view of the
Interpersonal Self

decreased
HCP

