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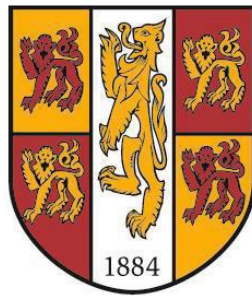
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**Exploring healthcare professionals' experiences of
providing care for people with dementia across the
lifespan.**

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PRIFYSGOL
BANGOR
UNIVERSITY

Submitted as partial fulfilment for the degree of Doctorate in
Clinical Psychology

June 2023

Declaration

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.

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 deuol cymeradwy.

Signed:  Stephanie Browne 30.05.2023

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Thesis Abstract

This thesis explores healthcare professionals' experiences of providing care for people with dementia across the lifespan. The first chapter is a systematic review of the contemporary research on healthcare professionals' attitudes towards, and experiences of, assisted dying in people with dementia. Sixteen papers were included in the review. There was no consensus view on assisted death in dementia, rather healthcare professionals' attitudes towards, and experiences of, this practice appeared to be influenced by clinical, professional, and personal factors, as identified through the quantitative data reviewed. Thematic synthesis identified four themes from qualitative data; challenges physicians faced, contextual factors, personal impact on physicians, and alternatives to assisted deaths. Clinical implications to better support healthcare professionals around this practice were discussed.

The second chapter explores the experiences of mental health nurses working with people with young onset dementia in the United Kingdom. Using a qualitative study design, eight nurses were interviewed about their lived experiences of work with people with young onset dementia, and their families. An interpretative phenomenological analysis framework was used, and three group experiential themes were developed; tensions between personal and professional lives, systemic challenges faced by young onset dementia nurses, and unique aspects of the young onset dementia nurse role. Recommendations for how nurses working in this area can be better supported clinically, are discussed.

The third chapter considers the clinical implications of the systematic review and the empirical paper and offers ideas for future research in these areas. This chapter also includes a personal reflective commentary on the research process.

Chapter One

Systematic Review

**Assisted dying for people with dementia: A systematic review of
healthcare professionals' attitudes and experiences.**

Assisted dying for people with dementia: A systematic review of healthcare professionals' attitudes and experiences.

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Abstract

With growing legislation to support assisted dying worldwide, this systematic review aimed to provide a contemporary exploration of healthcare professionals' attitudes towards, and experiences of, assisted dying in people with dementia. Four electronic databases (CINAHL Plus, PsychINFO, PubMed, ASSIA) were searched between January 2010 and April 2023. Sixteen studies met inclusion criteria and were reviewed using narrative and thematic syntheses. Results indicated several clinical, professional, and personal factors which influenced healthcare professionals' attitudes towards, and experiences of, assisted dying in people with dementia. Qualitative findings further explored challenges physicians faced, the influence of contextual factors, the personal impact of assisted dying requests and practices, and potential alternatives. Implications for future research and clinical practice are also discussed.

Introduction

Assisted dying is the subject of moral and ethical debates worldwide. With a growing number of jurisdictions legalising forms of assisted dying, there is increased interest in its' appropriateness and applicability for people with dementia.

Terminology

Assisted dying, as defined by the European Association of Palliative Care, encompasses both euthanasia, in which a physician administers a lethal dose of medication to an individual at their voluntary and competent request, and physician-assisted suicide, whereby an individual self-administers the lethal dose of medication provided by a medical professional at the individual's voluntary and competent request (Materstvedt et al., 2003; Radbruch et al., 2016). In some jurisdictions, 'medical assistance in dying' is a term used synonymously (Rajkumar, 2021). Withholding or withdrawing life-sustaining treatments are not considered forms of assisted dying, as these measures allow an (imminent) death from an underlying medical condition rather than actively ending life (Radbruch et al., 2016). Similarly, palliative sedation is not considered within this framework, as its' intention is to relieve suffering not hasten death (Cherny et al., 2009).

In this review, healthcare professionals (HCPs) are individuals who are qualified with a registered profession and either directly involved in the care of people with dementia or working within settings where they will encounter people with dementia, e.g., General Practitioners (GPs) and Elderly Care Physicians (ECPs).

Current Legislation

Assisted dying, subject to strict conditions, is permitted in a growing number of jurisdictions, including Austria, some Australian states, Belgium, Canada, Colombia, Germany, Luxembourg, the Netherlands, Spain, Switzerland, 10 American states, and the District of Columbia, though the mechanisms of assisted dying, and which individuals can access it, varies (Dom et al., 2020; Emanuel et al., 2016; Grassi et al., 2022; Mondragón et al., 2020). To avoid prosecution in countries where assisted dying frameworks are in place, physicians must follow due care criteria (DCC). In the Netherlands, they must also notify one of the Regional Euthanasia Review Committees (RERC) of each assisted death. The DCC, or equivalent, vary across jurisdictions, but are largely aligned with the Dutch criteria (Table 1).

Table 1

Dutch Due Care Criteria (DCC) for Assisted Dying (RERC, 2022b)

Criterion Description	
1.	The physician must be satisfied that the patient's request is voluntary and well considered.
2.	The physician must be satisfied that the patient's suffering is unbearable, with no prospect of improvement.
3.	The physician must have informed the patient about their situation and prospects.
4.	The physician must have come to the conclusion, together with the patient, that there are no reasonable alternatives in the patient's situation.
5.	The physician must have consulted at least one other, independent physician, who must see the patient and give a written opinion on whether the DCC set out in 1-4 have been fulfilled.
6.	The physician must have exercised due medical care and attention in terminating the patient's life or assisting in the patient's suicide.

In England and Wales, it is an offence to assist the suicide of another person (Gajjar & Hobbs, 2022) and euthanasia is illegal across the United Kingdom (UK; Gajjar & Hobbs, 2022). However, in 2021, Jersey's States Assembly became the first UK parliament to agree in principle that assisted dying should be allowed for individuals with either a terminal illness or an incurable physical condition causing unbearable suffering (Government of Jersey, 2022).

Views of HCPs on Assisted Dying

The views of HCPs towards assisted dying are divergent. Some consider it an extension of holistic care (Beuthin et al., 2018) and a way of empowering individuals with incurable illnesses to take control of their lives and maintain dignity in death (Sellars et al., 2021). Others feel that assisted dying does not align with the concept of a 'good death' and believe that responsive, compassionate palliative care better relieves suffering and permits a natural dying process (Blaschke et al., 2019). Given these dilemmas, in countries where there is a legal framework around assisted dying, there are measures, such as conscientious objection, which permit HCPs to opt out of participating in these practices if they conflict with moral or religious beliefs (Pesut et al., 2018).

Assisted Dying in Dementia

As the population ages, the number of people living with dementia is likely to increase (Prince et al., 2015). While some individuals will retain satisfactory quality of life (QoL), others may wish to request assistance in dying, if they determine their suffering, or fear of future suffering, to be unbearable (Dehkhoda et al., 2021). Fear of losing independence, dignity, competence, and sense of self, or becoming burdensome or dependent on others, may also underlie wishes for an assisted death

(Diehl-Schmid et al., 2017; Gastmans & De Lepeleire, 2010; Monforte-Royo et al., 2012).

Assisted death whilst a person with dementia has mental capacity for decision-making, likely in the earlier stages, is permissible in the Netherlands, Luxembourg, Belgium, Colombia, Canada, and Switzerland (Marijnissen et al., 2022). Assessing capacity for decision-making is a challenge for physicians who receive requests for assisted deaths in later stage dementia. Currently, the Netherlands is the only jurisdiction where people with dementia can write an Advanced Euthanasia Directive (AED), which can replace a concurrent oral request for assisted death when the person no longer has capacity to make this decision (e.g., in advanced dementia), provided all other obligatory criteria are met (RERC, 2022b). In Belgium and Luxembourg, AEDs are only applicable if the person is in a state of irreversible unconsciousness (i.e., a coma), while in Colombia they are only applicable where death is imminent (Bravo et al., 2018b). In Canada, recent legislative changes allow people who meet criteria for an assisted death to request this be performed at a specified later date, should they lose capacity before then, however, this is only permissible for people whose natural death is reasonably foreseeable (Government of Canada, 2023). It is therefore unclear to what extent this could apply to people with advanced dementia.

Another challenge surrounding assisted death in people with dementia is the perceived nature of suffering. Although most legislation stipulates that individuals must be suffering 'unbearably,' the nature of dementia means there are often fluctuations in mood and communication, making it difficult to assess suffering (Diehl-Schmid et al., 2017).

Despite these challenges, and whilst remaining a small proportion of all assisted deaths, the number of assisted deaths in dementia has risen recently. In the Netherlands in 2011, 49 reports out of 3,695 assisted deaths were for people with dementia (RERC, 2012), whilst in 2021, this increased to 215 out of 7,666 (RERC, 2022a). Of these 215 cases, 209 had early-stage dementia, while six had advanced, or very advanced, dementia (RERC, 2022a). There was also a gradual increase in assisted deaths for people with dementia in Belgium, from five cases in 2008 to 14 cases in 2013 (Dierickx et al., 2017).

Existing Literature and Current Context

A previous review of the attitudes of HCPs, patients, carers, and the public towards assisted dying in dementia found varying responses (Tomlinson & Stott, 2015). The public were most accepting of people with severe dementia who had requested assisted dying when they had capacity, whilst people with dementia and their carers were generally more supportive in the earlier stages. Most HCPs opposed assisted dying, irrespective of dementia stage; however, some were more accepting in milder stages, where there was an agreed AED, and in jurisdictions where assisted dying in dementia was legalised (Tomlinson & Stott, 2015).

Since this review was published, debate on assisted dying in dementia has continued. In 2018, a Dutch physician who assisted in the death of a person with advanced dementia based on an AED was prosecuted, having been accused by two Regional Review Committees of not complying with DCC (Miller et al., 2019). This prompted critical media attention, resulting in a petition signed by physicians against the practice of what they deemed 'sneaky euthanasia' (Miller et al., 2019). The physician was later acquitted by the Criminal Court, a ruling upheld by the Dutch

Supreme Court in 2020 (Marijnissen et al., 2022). However, this case demonstrates the complexity and strength of feeling on this subject, even amongst HCPs in jurisdictions where this practice is legal.

Given the pace of legalisation of assisted dying worldwide, the recent legal case, and the potential for changes in attitudes towards assisted dying in dementia, it was considered that a contemporary review, focused on attitudes and experiences of HCPs, was timely.

Aim of Review

This systematic review aimed to explore contemporary research on HCPs' attitudes towards, and experiences of, assisted dying in people with dementia. This included whether HCPs support the practice, as well as some descriptions of contexts which may influence views (e.g., whether in early or late-stages of dementia or whether an AED had been completed).

The question asked in this review is: "What are healthcare professionals' attitudes towards, and experiences of, assisted dying in people with dementia?"

Method

This review was registered with PROSPERO in March 2023, number CRD42023402312. It was undertaken according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines (Page et al., 2021).

Eligibility Criteria

Qualitative and quantitative studies were included if they were written in English, published in peer-reviewed journals, and reported empirical data. Theses, review articles, conference presentations and abstracts were excluded. To ensure a

contemporaneous review of the literature, only studies published since January 2010 were eligible. See Table 2 for additional inclusion and exclusion criteria.

Table 2

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Papers which include views of people with dementia, carers of people with dementia, or the public, where it is possible to extract the views of HCPs.	Papers focused on reviews or legislation around assisted dying in dementia.
Papers which include views of HCPs' towards assisted dying, where it is possible to extract their views specifically related to assisted dying in people with dementia.	<p>Papers focused on HCPs' views or experiences of assisted dying, where it is not possible to extract their views related to assisted dying in dementia specifically.</p> <p>Papers focused on HCPs' views or experiences of deep continuous sedation or withholding of artificial nutrition and hydration.</p> <p>Papers focused solely on the views of people with dementia or informal carers or families of people with dementia, on assisted dying in dementia.</p>

Search Strategy

The review used a two-stage search strategy. Four electronic databases (CINAHL Plus, PsychINFO, PubMed, ASSIA) were searched up to 1st April 2023,

followed by forwards and backward hand-searches of the reference lists and citations of eligible studies. The search terms used are included in Table 3.

Table 3

Search Terms

General Domain	Search Terms
Healthcare Professional	(Healthcare professional* OR nurse* OR doctor* OR physician* OR professional* OR social worker* OR clinician* OR occupational therapist* OR psychologist* OR physiotherapist*) AND
Assisted Dying	(Assisted dying OR assisted suicide OR euthanasia OR physician assisted death OR physician assisted suicide OR medical assistance in dying OR hasten* death OR death with dignity OR dying with dignity) AND
Dementia	(Dementia OR Alzheimer* OR vascular dementia OR mixed dementia OR Lewy Body dementia OR young onset dementia OR frontotemporal dementia OR primary progressive aphasia OR semantic dementia OR posterior cortical atrophy).

Searches were undertaken by the first author, with papers screened against inclusion/exclusion criteria. Cross-checks were undertaken independently by the second author on a proportion of papers at each stage of selection.

Data Collection

A data extraction form was created and used to gather relevant information from each study including; design, country of origin, legal status of assisted dying in

dementia at the time of the study, type of HCPs involved in study, main aims, and findings.

Quality Assessment

The quality of studies was assessed using the Mixed Methods Appraisal Tool (Hong et al., 2018), which discourages excluding studies based on low methodological quality. Quality appraisals were undertaken by the first author, with cross-checks undertaken independently by the second author; disagreements were resolved by discussion until consensus was reached.

Method of Synthesis

Due to heterogeneity in design, methods, and type of data collected in included studies, a narrative approach was used to synthesise findings (Popay et al., 2006). The review followed the six main elements of a narrative synthesis, as described by Popay and colleagues (2006); identifying the review focus, specifying the review question, identifying studies to include in the review, data extraction and quality appraisal, synthesis, reporting the results and dissemination. A thematic synthesis approach was used on the qualitative data arising from included papers. This followed the three-stage process outlined by Thomas and Harden (2008): line-by-line coding of the findings of the included qualitative data, before organising codes into descriptive themes, which were later developed into analytical themes.

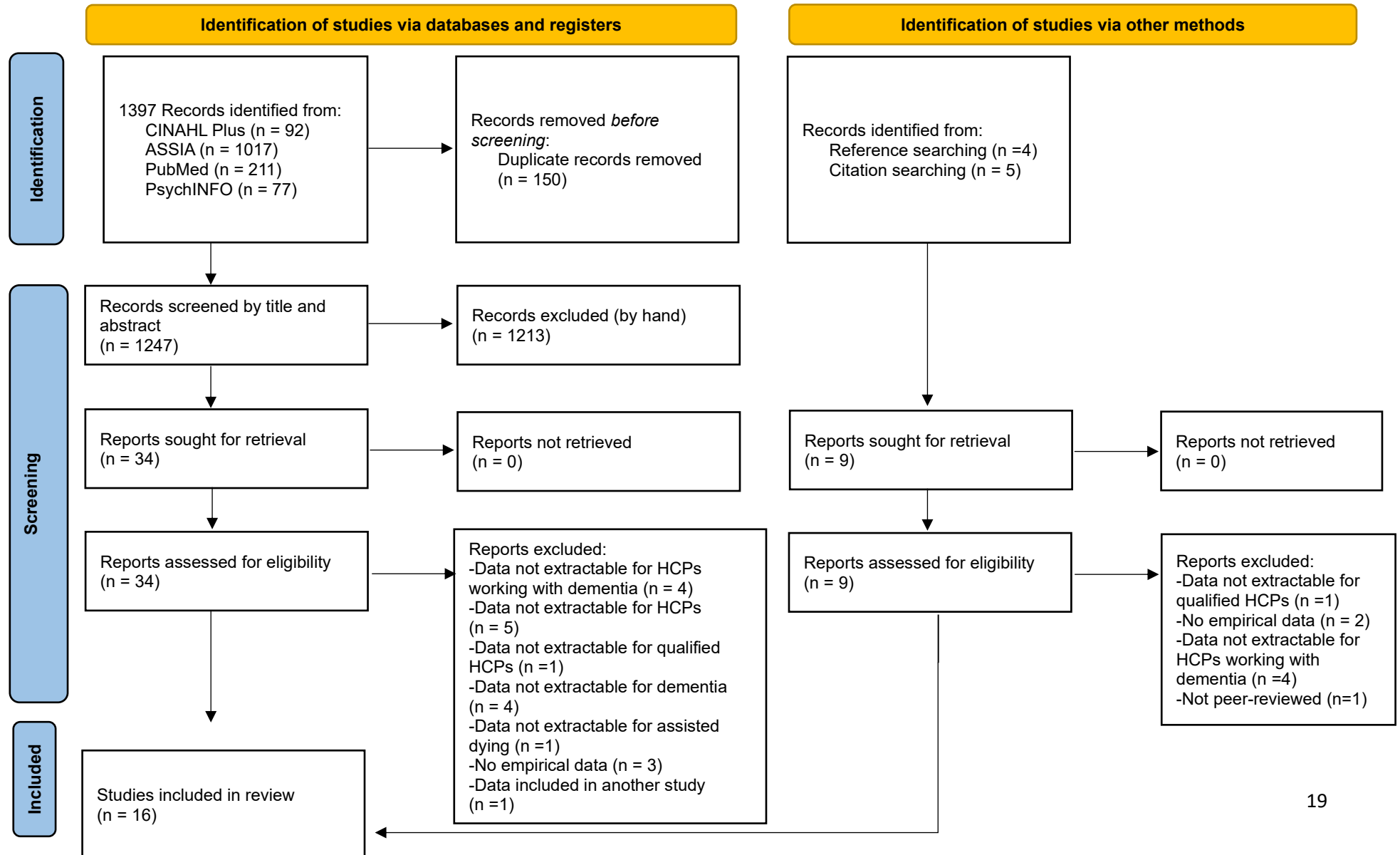
Results

Study Selection

Search results from each database – totalling 1397 papers – were exported to reference management software where duplicates were removed. The titles and abstracts of the remaining 1247 articles were screened by the first author against the inclusion/exclusion criteria. Full texts were retrieved for 34 studies, with 19 removed for not meeting eligibility criteria. A proportion of these were cross-checked by the second and third author. Following citation and reference searching, an additional study was found. The final study inclusion count was 16. The study selection process is depicted in Figure 1.

Figure 1

PRISMA Flow Diagram of Study Selection



Overview of Studies

Table 4 provides an overview of the quantitative and mixed-methods studies, while Table 5 summarises the qualitative studies.

Most studies were quantitative in design ($n=10$), with four mixed-methods, and two qualitative studies. The HCPs involved were predominately physicians, though one study focused on nurses and another on social workers. Sample sizes ranged from 11 to 995 participants. Studies were predominately conducted in the Netherlands ($n=9$); a smaller proportion were completed in Canada ($n=4$), Belgium ($n=2$), and Switzerland ($n=1$).

At the time of the studies, assisted dying was permissible across all dementia stages in the Netherlands. In Quebec, the province where the Canadian studies were completed, at the time of the earlier studies (Bravo et al., 2018a, 2018b, 2022a) assisted dying was limited to people at the end of life if mentally competent (Health Canada, 2022). In 2021, when the most recent Quebecois study (Bravo et al., 2022b) was conducted, assisted dying was permitted for people whose death was not reasonably foreseeable; however, individuals were required to consent immediately prior to an assisted death (Government of Canada, 2023). In Belgium and Switzerland, assisted dying was permissible in people with dementia who were competent at the time.

Most studies used questionnaires ($n=14$), with some also including clinical vignettes ($n=6$). The two qualitative studies used semi-structured interviews. Three sets of studies drew from the same samples but reported different data (Bravo et al., 2018b, 2022a; de Boer et al., 2010, 2011; Schuurmans et al., 2020, 2021).

Table 4

Overview of Quantitative and Mixed-Method Studies

Author(s), Publication Year	Country, Legal Status of Assisted Dying in Dementia at Time of Study	Professionals (dementia)	Study Design / Method	Main aim	Summary of Key Results
Bolt et al., 2015	The Netherlands Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.	Random sample of GPs (n=708) and ECPs (n=287)	Cross-sectional Postal or online questionnaire.	Describe whether physicians could conceive of granting request for EAS (or have granted such requests) in patients with cancer, other physical disease, psychiatric disease, dementia, or tired of living (in the absence of severe disease). Identify physician characteristics influencing conceivability – including age, gender, religiosity, time working in speciality, whether trained in PC, SCEN physician and patient deaths in previous year.	Conceivability of performing EAS in dementia: <ul style="list-style-type: none">• Early stage: GPs (44%) / ECPs (47%).• Advanced, no comorbidities: GPs (34%) / ECPs (14%).• Advanced, all cases: GPs (31%) / ECPs (10%) In advanced dementia, ECPs less likely to conceive of EAS. Two factors influenced conceivability in all causes of suffering: religiosity and being a SCEN physician. Age, being a PC consultant, and number of patient deaths in last year, not related to conceivability.
Bravo et al., 2018a Part of a large research project investigating the views of various stakeholders towards MAiD for incompetent patients.	Canada (Quebec) MAiD available to competent adults whose death is reasonably foreseeable (Canada) or who are at end of life (Quebec) subject to eligibility criteria.	Random sample of nurses (N = 291). Working in geriatrics, gerontology, or end-of-life care in public healthcare for patients with dementia.	Cross-sectional Postal questionnaire, plus clinical vignettes with multiple-choice questions and free-text space for comments.	Explore attitudes towards MAiD / CDS and extending MAiD to incompetent patients, reasons for attitudes, value attached to proposed safeguards. Identify sociodemographic factors influencing attitudes – including age, gender, religiosity, time working in speciality, work environment, training in PC, exposure to MAiD requests from patients/family. Review personal preferences for MAiD or personal experience with family /friends.	Support to extend MAiD to incompetent people with dementia who do not seem uncomfortable: 53% with advance request written when competent, 26% without. In terminal stage, if distressed, support increased to 83% with written request, 52% without. Three factors predictive of attitudes: 1) having accompanied a dying relative/friend through the process; 2) being <i>likely</i> to make own MAiD request if dementia diagnosed; 3) being <i>likely</i> to ask physician to carry out advance request (made when competent) for now-incompetent relative.
Bravo et al., 2018b Part of a large research project investigating the	Canada (Quebec) MAiD available to competent adults whose death is reasonably	Random sample of physicians (N=136). GPs (n=62); Other specialities (e.g., geriatrics, neurology; n=74).	Cross-sectional Postal questionnaire, plus clinical vignettes with multiple-choice questions and free-	Explore physicians' attitudes towards extending MAiD / CDS to incompetent patients with dementia, and willingness to be involved if legal.	Advanced dementia: 45% favoured MAiD if advance request written with capacity; 14% for repeated oral requests. Of 121 physicians caring for patients with advanced dementia, 31% likely to administer MAiD themselves if advance written request present, 14% with repeated oral requests when competent.

views of various stakeholders towards MAiD for incompetent patients.	foreseeable (Canada) or who are at end of life (Quebec) subject to eligibility criteria.	All caring for people with dementia.	text space for comments.	Secondary objective, compare views of GPs vs. other medical specialists (involvement in MAiD known to differ).	In terminal stage, 71% favoured MAiD with written request; 43% with repeated oral requests. If caring for terminal patients, 54% likely to administer MAiD themselves with written request; 32% without. GPs more likely to administer MAiD in advanced and terminal dementia.
Bravo et al., 2022a	Canada (Quebec) MAiD available to competent adults whose death is reasonably foreseeable (Canada) or who are at end of life (Quebec) subject to eligibility criteria.	Random sample of physicians caring for patients with dementia at the time of the survey (N=136). This study used data from Bravo et al., 2018b study on physicians	Cross-sectional Postal questionnaire, clinical vignettes.	Comparing demographic and practice characteristics of respondents according to (1) open or not to extending MAiD to non-competent patients with dementia, and (2) willing or not to administer MAiD if legal, separately for advanced and terminal stages of dementia.	In advanced dementia: religiosity and exposure to assisted dying requests significantly predicted openness to extend MAiD to non-competent dementia patients. Only religiosity predicted willingness to administer MAiD if legal. In the terminal stage: age, training in PC, practicing in a teaching hospital, and exposure to assisted dying requests from families predicted openness to extend MAiD to non-competent dementia patients. Only practicing in a teaching hospital and exposure to assisted dying requests from families predicted willingness to administer MAiD if legal. Physicians who were older, more religious, had training in PC, practiced in a teaching hospital, and had not received assisted dying requests in previous 12 months had less favourable attitudes towards MAiD in dementia.
Bravo et al., 2022b	Canada (Quebec) MAiD available to competent adults subject to updated eligibility criteria.	Random sample of social workers whose practice involved people with dementia (N=367).	Cross-sectional Online and postal questionnaire (see Bravo et al., 2018a; Bravo et al., 2018b) and clinical vignettes.	Elicit social workers' attitudes toward MAiD / CDS for people with dementia, with a focus on those lacking capacity. Assess the values and beliefs underlying them; compare attitudes to those of nurses and physicians. Identify sociodemographic factors influencing attitudes and explore perceived competence and support needs.	Acceptability in early-stage dementia was low (42%), increasing to 92% by terminal stage with advance written request. Acceptability of MAiD higher with written request than without, at all stages. Willingness was lower in absence of written request at any stage. One-third would not participate in MAiD provision for a still-competent person with early-stage dementia. One-third were concerned that people without decision-making capacity may receive MAiD against their will. Social workers were more favourable to extending MAiD to the incompetent person than physicians or nurses.
Brinkman-Stoppelenburg et al., 2020 Conducted as part of the third evaluation of the Termination of Life on Request and Assisted Suicide (review procedures) Act.	The Netherlands Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.	Random sample of GPs (n=607) and NHPs (n=209)	Cross-sectional Written questionnaire	Explore opinions of public and physicians on euthanasia in patients with advanced dementia who are incompetent to consent to care. Identify factors associated with acceptance of euthanasia in patients with dementia. Research questions:	Only 3.2% of GPs and 5.4% of NHPs had received euthanasia requests from dementia patients in past year – 0.7% of GPs and 1.5% of NHPs had performed euthanasia in this group. Around half of GPs and NHPs found euthanasia conceivable in competent early-stage dementia. Conceivability in advanced dementia (with written advance directive and without comorbidities) was 24% for GPs and 8% for NHPs. Religious belief, sex, specialty, having received euthanasia requests and having performed euthanasia all significantly

- To what extent do physicians consider performing euthanasia in patients with advanced dementia conceivable?
- Which demographic or professional characteristics are associated with positive attitudes toward euthanasia in advanced dementia?

associated with considering performing euthanasia conceivable in advanced dementia.

Having ever performed euthanasia before was positively associated finding euthanasia conceivable. Being female, having religious beliefs, and being a NHP all negatively associated with conceivability.

Cleemput & Schoenmakers, 2019	Belgium Permissible for people with dementia who can express their wishes at the time of assisted death being performed.	Random sample of Flemish GPs (n=113)	Cross-sectional, mixed methods Online survey. Based on existing questionnaire (Kouwenhoven et al., 2015; Bravo et al., 2017) with additional questions.	Opinions of Flemish GPs on euthanasia in patients with dementia under the current legislation and on euthanasia in general.	52% agreed that euthanasia in people without dementia felt more acceptable than in those with dementia. <i>Agreement (disagreement) with acceptability of euthanasia in dementia stages:</i> <ul style="list-style-type: none"> • Early-stage: 44% (46%) • Progressive: 51% (39%) • Advanced: 65% (29%) • End-stage: 72% (24%) Non-religious GPs more willing to perform euthanasia in all stages – difference greater in early (50% vs.15%) and end-stage (81% vs. 56%). Non-religious GPs almost twice as likely to favour legal change compared to religious (66% vs. 37%). Overall, 43% agreed laws needed changing for dementia. Legal change encouraged more by younger GPs compared with GPs aged >40 (63% vs. 48%). If law allowed euthanasia, confirmed by AED in dementia, 72% feared pressure from relatives without consent by patient at the decisive moment. 41% had unconditional positive attitudes towards euthanasia in dementia; 20% would never consider it, and 12% insisted on shared decision with patients, relatives, and carers.
de Boer et al., 2010 Part of a larger study on advance care planning in dementia.	The Netherlands Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.	Random sample, ECPs (N=434)	Cross-sectional Written questionnaire	Gain insight into current practices around AEDs and euthanasia in people living with dementia in nursing homes who were no longer considered competent. Explore relationships between views and participant variables (e.g., age, sex, working experience, religion, thoughts on performing euthanasia in the future).	Most (73%) disagreed that dementia can be a valid reason for life-terminating actions; disagreement higher in ECPs with a religious background. In total, 76% agreed it impossible to determine when AED in dementia should be carried out - 54% believed it impossible to determine if an incompetent person with dementia in 'unbearable or hopeless suffering'. 40% of ECPs who had not performed euthanasia in dementia considered it conceivable they might in the future; 40%

				<p>inconceivable, 20% did not know. Most (75%) ECPs who thought they might perform euthanasia in dementia added that the patient would have to be competent.</p> <p>ECPs considering euthanasia conceivable were older and more often working in nursing homes allowing AED compliance. ECPs considering it inconceivable to perform euthanasia in dementia were more often religious.</p>	
<p>de Boer et al., 2011</p> <p>Part of a larger-scale study</p>	<p>The Netherlands</p> <p>Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.</p>	<p>Random sample of ECPs (N=434).</p> <p>Questionnaire (n=434); Interviews (n=11)</p> <p>This study used same sample as de Boer et al. (2010) study but had different focus.</p>	<p>Cross-sectional, mixed methods</p> <p>Written postal questionnaire, plus interviews with physicians (of people with dementia and an AED who had died.)</p>	<p>Gain insight into the way AED of people with dementia affect resident care in nursing homes and identify any changes in this since the introduction of new euthanasia law by comparing results with data from previous research.</p> <p>Highlight experiences of ECPs of people with dementia who had an AED.</p>	<p>Five ECPs had performed euthanasia on a person with dementia (with AED) – all competent. None had adhered to a dementia AED if incompetent.</p> <p>Reasons for not adhering to AED in dementia:</p> <ul style="list-style-type: none"> • No unbearable suffering (38.2%). • Nursing home policy does not allow euthanasia (15.5%). • Personal beliefs do not allow it (15.5%) • Person was not in situation the AED intended for (15.5%). • No hopeless suffering of the patient (12.7%). <p>Other:</p> <ul style="list-style-type: none"> • Opinion impossible to determine / no communication (10%). • Patient currently has no wishes (5.5%). • Does not want euthanasia / does not want to die (4.5%). • Patient is incompetent (4.5%). • Relatives do not want euthanasia (4.5%). <p><i>Interviews:</i></p> <p>ECPs' personal (e.g., religious) beliefs stopped them considering euthanasia. Active requests for euthanasia by the person was essential - communication essential to determine suffering. Some believed AEDs gave false hope. Despite legal possibilities, AEDs rarely complied with, and never in advanced dementia.</p>
<p>Loizeau et al., 2019b</p> <p>Data taken from larger study (Loizeau et al., 2019a)</p>	<p>Switzerland (Swiss German region)</p> <p>Physician-assisted suicide only legal for those with capacity to consent at the time.</p>	<p>Physicians (n= 64) (Swiss Association for Palliative Medicine, Care and Support, and the Swiss Geriatric Medicine Society)</p>	<p>Cross-sectional</p> <p>Postal written questionnaire</p>	<p>Describe physician and surrogate agreement with the use of CDS and assisted dying in advanced dementia.</p> <p>Compare agreement with use of these practices in these two groups.</p>	<p>Physician agreement with assisted dying:</p> <ul style="list-style-type: none"> • Completely agree (4.7%), • Somewhat agree (15.6%) • Somewhat disagree (26.6%) • Completely disagree (50%) • Do not know (3.1%) <p>Variables associated with agreement: age >55 years; prior major treatment decision in dementia; being a professional guardian/surrogate (vs. a physician).</p>

After multivariable adjustment, only being a surrogate (vs. a physician) remained significantly associated with a higher likelihood of agreeing with assisted dying.

Picard et al., 2019	Belgium Permissible for people with dementia who can express their wishes at the time of assisted death being performed.	Purposive sampling Physicians (N = 17) Expert members of Belgian Dementia Council.	Cross-sectional, mixed methods Online questionnaire, multiple-choice questions with some free-text spaces. Survey sent following a debate amongst members of the Belgian Dementia Council on end-of-life decisions, including euthanasia in people with dementia.	Investigate experiences and opinions of specialist dementia physicians on dementia and advance care planning, dementia, and euthanasia according to current Belgian law, and the possible extension of law to allow AED in dementia.	<p>Most (76%) agreed with current law on euthanasia in dementia.</p> <p>Only 53% felt comfortable with euthanasia questions; 94% believed patients/families poorly informed about law. 10/16 had received at least one dementia euthanasia request that did not fulfil legal criteria. 15/17 had received valid requests.</p> <p>65% were against extending the law based on AED, 35% supported the change. No differences between those for/against in terms of sex, linguistic community, specialty, practice, years of professional experience, number of dementia patients seen per year, or % with severe dementia.</p> <p>Reasons against extensions: lack of consensus on selection criteria and preference for PC. Most against the extension (9/11) believed it would not meet patients' needs. Those in favour proposed patients define in ACP personal criteria for when euthanasia performed.</p> <ul style="list-style-type: none"> • 50% of those in favour of extending the law were willing to perform euthanasia unconditionally – the remainder if conditions met. One physician would not perform it at all. • Considered important that patient confirmed choice, patient and GP known well, confirmation received from colleagues, and decisional capacity evaluated. • Most, in favour and against, wanted confirmation of patient wishes in progressed dementia. <p>For 59%, it was important to include relatives in decision-making, but final decision should respect patient's will.</p>
Schuurmans et al., 2020	The Netherlands Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.	Representative sample of Dutch GPs (N=423) with or without experience with euthanasia requests, or performance in general, or with people with dementia.	Cross-sectional Postal survey with closed questions, multiple-choice questions, and some free-text space.	<p>Describing the experienced burden and support needs of Dutch GPs when met with a euthanasia request by a person with dementia.</p> <p>Explore wishes for further training to increase skills and knowledge around dementia.</p> <p>Discover whether recent discussions around euthanasia in people with</p>	<p>In total, 41.6% had received a euthanasia request from a patient with dementia. Of those, 22.7% had performed euthanasia in dementia – mostly in people who were still competent.</p> <p>Of those who had never performed euthanasia in dementia, 45.1% could imagine doing so in the future; 47.9% would refer a patient to a colleague or the Dutch Expert Centre for Euthanasia. Only, 7% would never perform euthanasia in dementia and never refer to a colleague.</p>

dementia (i.e., prosecution case) influenced GPs' practice.

Compared to other conditions, the burden of euthanasia requests / procedures was considered higher in dementia in terms of emotional burden, uncertainty about technical procedures, mental competence, and AEDs, pressure from patients, and time pressures.

Impact of recent court case involving physician on attitudes: 36.3% of GPs not influenced, 31.3% were more reserved in performing euthanasia in people with dementia, 24.2% were more fearful of legal processes, 21.1% intended to consult other HCPs more often, 19.4% were more likely to refer these patients to a colleague or the expert centre for euthanasia.

Support needs relating to requests / performance of euthanasia in people with dementia (past vs. future):

- PC consultation (20.9% vs. 42.3%)
- Geriatric team consultation (23.3% vs. 43.7%)
- Spiritual care provider (1.2% vs. 3.8%)
- Expert centre for euthanasia (31.9% vs. 43.5%)
- Moral deliberation (1.2% vs. 7.1%)
- PaTz-group (9.8% vs. 19.6%)
- SCEN physician (50.9% vs. 68.8%)
- Other (31.9% vs. 13.5%)

Schuurmans et al., 2021	The Netherlands Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.	Representative sample of Dutch GPs (N=423) GPs with or without experience with euthanasia requests or performance in general, or with people with dementia. This study used the same sample as Schuurmans et al., 2020, different aim.	Cross-sectional, mixed methods Postal survey with clinical vignette based on recent prosecution of a Dutch physician. Some closed questions, multiple-choice questions, and some free-text space.	Explore views of Dutch GPs on euthanasia in people with advanced dementia.	<p>Most (82.4%) agreed it was difficult to judge if due care criterion (unbearable suffering) was met if patient incompetent – 58.6% disagreed this could be met by competent person considering future suffering.</p> <p>Vignette based on court case: Did the GP act correctly? 42.2% (n=178) answered yes, 49.8% (n=210) answered no.</p> <p>Can an AED replace oral requests if communication with patient no longer possible?</p> <ul style="list-style-type: none"> • Agree (18%). • Disagree (42.2%) • Maybe (37.4%) <p>Can family initiate a euthanasia procedure representing the interests of a person with advanced dementia?</p> <ul style="list-style-type: none"> • Agree (22.5%). • Disagree (49.5%) • Maybe (26.1%) <p>Open text explanations: only if GP knows family/ patient well; if patient authorised relative when competent; if family</p>
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					participated in earlier conversations; and if no pressure from family or conflict of interests.
van Tol et al. 2010	The Netherlands Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.	Random sample of GPs (N = 115)	Cross-sectional Written questionnaire. Clinical vignettes based on different types of suffering, followed by closed questions.	Examine how physicians interpret the unbearable suffering criterion when presented with euthanasia requests, and whether this is associated with willingness to grant a request. To explore how this may be linked to physician characteristics.	In clinical vignettes, Only 2% agreed that a case involving early-stage dementia met criteria for unbearable suffering, 39% disagreed, and 59% felt it may meet criteria for patient, but not for the GP. The concordance rate between judgement of suffering and willingness to grant a request in early-stage dementia was 96%. The only significant association found between physician characteristics and judgement of unbearable suffering / willingness to carry out a euthanasia request was experience with euthanasia. Overall, GPs who performed euthanasia at least once in the past 5 years more often considered suffering to be unbearable and were more willing to grant a request.

Note: AED: Advanced Euthanasia Directive, CDS: Continuous deep sedation, EAS: Euthanasia/Assisted suicide, ECP: Elderly Care Physician, GP: General Practitioner, MAiD: Medical Assistance in Dying, NHP: Nursing home physician, PC: Palliative care, PaTz group: interprofessional meetings to identify patients with palliative care needs. SCEN physician: Support and Consultation on Euthanasia in the Netherlands.

Table 5

Overview of Qualitative Studies

Author(s), Publication Year	Country, Legal Status of Assisted Dying in Dementia at Time of Study	Professionals	Study Design / Method	Main aim	Summary of Key Findings
Coers et al. (2023)	The Netherlands Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.	Purposive selection Physicians (N = 12) registered on 'no sneaky euthanasia' website, which refers to euthanasia based on AED where the patient does not realise what is happening. GPs, n=5 ECPs, n=7	Cross-sectional Semi-structured interviews Constant comparison method, thematic content analysis and the framework method	To gain insight into the experienced dilemmas of physicians who supported the 'no sneaky euthanasia' petition, and to identify topics in need of more guidance.	<i>Reasons for supporting the petition, beyond opposition to 'sneaky euthanasia':</i> -Dilemmas concerning 'sneaky euthanasia.' -The over-simplified societal debate. -Personal moral boundaries. -The growing pressure on physicians. <i>Underlying motives for supporting the petition:</i> -Aspects of handling a euthanasia request based on AED. -Good end-of-life care. -The doctor as a human.
Schuermans et al., 2019	The Netherlands Permissible across all stages of dementia. AED required when person no longer has capacity to make concurrent decisions on assisted dying.	Purposive and snowballing recruitment of physicians with varied experience in granting euthanasia for people with dementia, N = 11, GPs, n = 5, ECPs, n = 6 Recruited from critical statement published in Dutch newspapers which opposed euthanasia in advanced dementia, and the End-of-Life clinic (later known as Euthanasia Expertise clinic). 10 had signed the statement. 2 were employed at the End-of-Life clinic.	Cross-sectional Semi-structured interviews Direct content analysis approach, thematic content analysis, resulting in five themes.	To get more insight into the impact, experiences and needs of Dutch GPs and ECPs when handling a euthanasia request from a person with dementia.	<i>1.Evaluation of the euthanasia request:</i> Reasons for rejection: too late in dementia trajectory, no repeated clear request, mental incompetence. Reasons for acceptance: unbearable suffering in the future, has to feel right, repeated clear convincing request. <i>2.Difficulties experienced by doctors:</i> Timing, workload, pressure by relatives, influence from society, patient-doctor communication, law, due care criteria and the guidelines. <i>3.Expertise:</i> Individual level, organisational level <i>4.Support and coping:</i> Improvement of existing services, alternatives to euthanasia. <i>5.Doctor's emotions:</i> Negative, positive.

Note: AED: Advanced Euthanasia Directive, ECP: Elderly Care Physician, GP: General Practitioner.

Quality Appraisal

Overall, the included studies were of good quality, particularly the qualitative studies. There was some variability in the quality of the quantitative studies, particularly the mixed methods studies, where qualitative data was often not considered as comprehensively as quantitative data. An area of weakness was the high risk of non-response bias across most quantitative studies, which reported low-moderate overall response rates. An overview of the quality appraisals is displayed in Table 6.

Table 6*Overview of Quality Appraisal of Included Studies*

Study	Screening Questions		Qualitative					Quantitative descriptive					Mixed Methods				
	S1	S2	1.1	1.2	1.3	1.4	1.5	4.1	4.2	4.3	4.4	4.5	5.1	5.2	5.3	5.4	5.5
Bolt et al., 2015	Y	Y	-	-	-	-	-	Y	Y	Y	Y	Y	-	-	-	-	-
Bravo et al., 2018a	Y	Y	-	-	-	-	-	Y	Y	Y	Y	Y	-	-	-	-	-
Bravo et al., 2018b	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y					
Bravo et al., 2022a	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y	-	-	-	-	-
Bravo et al., 2022b	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y	-	-	-	-	-
Brinkman-Stoppelenburg et al., 2020	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y	-	-	-	-	-
Cleemput, & Schoenmakers, 2019	Y	Y	-	-	-	-	-	-	-	-	-	-	N	Y	N	Y	N
Coers et al., 2023	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	-	-	-	-	-
de Boer et al., 2010	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y	-	-	-	-	-
de Boer et al., 2011	Y	Y	-	-	-	-	-	-	-	-	-	-	Y	Y	Y	Y	Y
Loizeau et al., 2019b	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y	-	-	-	-	-
Picard et al., 2019	Y	Y	-	-	-	-	-	-	-	-	-	-	N	Y	Y	Y	N
Schuurmans et al., 2019	Y	Y	Y	Y	Y	Y	Y	-	-	-	-	-	-	-	-	-	-
Schuurmans et al., 2020	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y	-	-	-	-	-
Schuurmans et al., 2021	Y	Y	-	-	-	-	-	-	-	-	-	-	N	Y	Y	Y	N
van Tol et al., 2010	Y	Y	-	-	-	-	-	Y	Y	Y	N	Y	-	-	-	-	-

Note: Y: Yes, N: No, - = Not applicable

Quantitative Findings

The quantitative findings are organised according to the clinical, professional, and personal factors relating to HCPs' attitudes towards, and experiences of, assisted dying in dementia.

Clinical Factors

Experience of Assisted Deaths in Dementia

The number of HCPs who received requests, and provided assisted dying, for people with dementia, varied across studies. In the Netherlands, where this practice was legal, one study reported that 41.6% of GPs (n=176) had received requests, of which 22.7% had provided assisted deaths, mostly where the person was competent (Schuurmans et al., 2020).

Within the previous year, 3.2% of GPs and 5.4% of Nursing Home Physicians (NHPs) in another Dutch study had received requests, while smaller proportions had performed assisted deaths for people with dementia in that time; 0.7% of GPs and 1.5% of NHPs (Brinkman-Stoppelenburg et al., 2020).

In one Dutch study, only three physicians had performed assisted deaths for people with dementia, all of whom were competent at the time (de Boer et al., 2010). Although a smaller sample, a Belgian study reported that most physicians (15/17) had received valid requests for assisted deaths from people with dementia, which had been performed in <10 people per physician (Picard et al., 2019).

Assisted Dying at Different Stages of Dementia:

Several studies noted that views and experiences of assisted dying in dementia were informed by the stage of dementia.

Early-stage

In early-stage dementia, individuals typically had capacity to make health-related decisions. In this instance, acceptability of assisted deaths was relatively low (42%) amongst Canadian social workers (Bravo et al., 2022b). In Belgium, acceptability was marginally higher (44%) amongst GPs (Cleemput & Schoenmakers, 2019) whilst in Dutch studies, 44% of GPs and 47% of ECPs (Bolt et al., 2015), and around half of GPs and NHPs, found the practice of assisted dying in early-stage dementia conceivable (Brinkman-Stoppelenburg et al., 2020).

Progressive Stage

One Belgian study included a 'progressive' stage, operationalised as a period whereby people were disorientated to time and space and had difficulty recognising relatives; at this point, 51% (n=44) of GPs agreed that assisted dying, based on AEDs, was acceptable (Cleemput & Schoenmakers, 2019).

Advanced-stage

In advanced-stage dementia, people were defined as not having capacity to make health-related decisions. At this point, based on an AED in the Netherlands, 34% of GPs and 14% of ECPs found it conceivable they would perform assisted dying in people without severe comorbidities (Bolt et al., 2015). Another Dutch study, which asked physicians whether they found assisted dying based on an AED conceivable at this stage, found smaller margins of conceivability, with 24% for GPs and 8% for NHPs (Brinkman-Stoppelenburg et al., 2020).

Studies also explored attitudes in jurisdictions where assisted dying was not legal. In vignettes, Bravo and colleagues (2018a, 2018b, 2022b) considered people dependent on others, living in residential care, but not distressed. Under these

circumstances, based on requests made while competent, 53% of nurses (Bravo et al., 2018a), 45% of physicians (Bravo et al., 2018b), and 66% of social workers (Bravo et al., 2022b) found assisted dying acceptable. At this stage, without advance agreements but with previous repeated oral requests, 26% of nurses (Bravo et al., 2018a), 14% of physicians (Bravo et al., 2018b) and 27% of social workers (Bravo et al., 2022b) supported assisted dying.

Slightly higher rates of acceptability were found in Belgium, where 65% of GPs considered the potential of assisted dying at this stage, based on advance agreements, acceptable (Cleemput & Schoenmakers, 2019). In a Swiss study, a lower proportion of physicians, 20.3%, agreed they would support assisted dying in advanced dementia, however here, there was no reference to advance agreements, which may have influenced responses (Loizeau et al., 2019b).

End-stage

This was considered the terminal stage approaching end of life. In vignettes, Bravo and colleagues (2018a, 2018b, 2022b) considered situations in which a person was distressed, must be spoon-fed, cries often, has a few weeks to live, and where efforts to control symptoms have been unsuccessful. At this stage, in the presence of a written advance agreement, 83% of nurses (Bravo et al., 2018a), 71% of physicians (Bravo et al., 2018b), and 92% of social workers (Bravo et al., 2022b) supported assisted dying. Without written advance agreements, but with repeated previous oral requests, 52% of nurses (Bravo et al., 2018a), 43% of physicians (Bravo et al., 2018b) and 64% of social workers (Bravo et al., 2022b) supported assisted dying. Similar agreement rates were observed in Belgian GPs, where 72% agreed that assisted dying based on advance agreement was

acceptable, though a slightly lower proportion, 62%, would administer this themselves (Cleemput & Schoenmakers, 2019).

Influence of Proposed Legislation and Legal Proceedings

Irrespective of differences in demographics or clinical experience, 65% of Belgian physicians were against a legislative extension to allow people with dementia to arrange assisted deaths for a later date; however, the sample was small (n=17; Picard et al., 2019). If legislation were passed to allow assisted dying in dementia based on AEDs, 72% (n=63) of GPs feared pressure from families to follow this without the person's concurrent consent (Cleemput & Schoenmakers, 2019).

One study (Schuurmans et al., 2020) asked whether GPs' views, or practice, of assisted dying in dementia were impacted by the recent prosecution of a Dutch physician. Here, 36.3% said they had not been influenced, 31.3% had become more reserved in their practice, 24.2% were more fearful of legal processes, 21.1% intended to consult other HCPs more often, and 19.4% were more likely to refer to colleagues or the Dutch Euthanasia Expertise Centre.

Schuurmans and colleagues (2021) gave Dutch GPs a vignette based on the legal case and found that 49.8% disagreed that the physician had acted correctly; 18% agreed that an AED could replace an oral request if communication was no longer possible; however, 42.2% disagreed with this, and 37.4% were unsure.

Non-Adherence to AEDs

In one Dutch study, 76% of ECPs agreed to an extent, that it was impossible to determine when a person with dementia's AED should be implemented (de Boer et al., 2010). In a later study, ECPs reported reasons for not adhering to AEDs in advanced dementia, including: believing the person was not suffering unbearably

(38.2%), or hopelessly (12.7%), workplace policy (15.5%) or personal beliefs (15.5%) not allowing it, not believing the person was in the situation the AED was intended for (15.5%), and believing the person's opinion was impossible to determine or communicate (10%; de Boer et al., 2011).

Due Care Criteria (DCC)

For some HCPs, level of agreement with, or acceptability of, assisted dying was influenced by whether they considered the DCC of unbearable suffering with no future improvement was, or could be, met in the context of dementia. Across two Dutch studies, 58.6% (n=247) of GPs in one study (Schuurmans et al., 2021) and 39% (n=45) in another (van Tol et al., 2010) disagreed that this criterion could be met in early-stage dementia.

When people had lost capacity, 54% of ECPs in a Dutch study considered it impossible to determine whether they experienced unbearable or hopeless suffering (de Boer et al., 2010). In a more recent Dutch study, a higher proportion, 82.4% (n=348) of GPs, agreed it was difficult to judge whether an incompetent person with dementia was suffering unbearably (Schuurmans et al., 2021). In Canada, 79.9% of nurses (Bravo et al., 2018a) and 83.8% of physicians (Bravo et al., 2018b) disagreed that it was 'impossible' to know whether an incompetent person unbearably suffered, however this was defined in these studies as 'unbearable physical pain.'

Workplace Influence

In one Dutch study, ECPs spoke about the influence workplace policy had on their experience of assisted dying requests from people with dementia (de Boer et al., 2010). Within this study, 63% of ECPs' workplace policies outlined that AEDs in dementia were not complied with but were considered within restricted treatment

frameworks, while 16% stated AEDs in dementia should never be complied with, and 14% said policies stipulated that AEDs in dementia could only be complied with if all DCC were met. Despite the variations, 88% of ECPs agreed with their workplace policies on assisted dying in dementia (de Boer et al., 2010).

Professional Factors

Differences amongst HCP Disciplines:

In one Dutch study, ECPs were significantly less likely to find it conceivable they would assist dying in advanced dementia than GPs (OR = 0.25-0.33; Bolt et al., 2015). Similarly, in a more recent Dutch study, NHPs were less likely than GPs (OR = 0.27, 95% CI: 0.15-0.47) to find this practice conceivable (Brinkman-Stoppelenburg et al., 2020). Following this trend, Bravo and colleagues (2018b) found that Canadian GPs considered assisted dying more acceptable than other physicians at the advanced and end stages of dementia, both with and without advance written requests. If the person was known to them, GPs were also significantly more likely than other physicians to administer assisted deaths in end-stage dementia ($p = .002$; OR = 3.2, 95% CI: 1.5-6.5) (Bravo et al., 2018b).

When demographic, personal, and professional factors were controlled for, nurses were significantly more supportive than physicians of assisted dying in end-stage dementia based on advance agreements ($p = .008$; OR = 2.9, 95% CI: 1.3-6.2; Bravo et al., 2022b). Social workers were more supportive than physicians of assisted dying in advance-stage dementia with prior written agreements ($p = .002$; OR = 2.3, 95% CI: 1.4-3.8) and in end-stage dementia with an advance agreement ($p < .001$; OR = 4.8, 95% CI: 2.5-9.2) and without an advance agreement ($p = .002$; OR = 2.2, 95% CI: 1.3-3.7; Bravo et al., 2022b).

Professional Experience

Physicians who had not received requests for assisted dying in the last year, as well as those working in teaching hospitals, and those trained in palliative care, were less supportive of assisted dying in dementia (Bravo et al., 2022a). Of those who had not performed assisted dying in a person with dementia based on an AED, 40% of ECPs considered it conceivable they may do so in the future, while 40% found this inconceivable, and 20% were unsure (de Boer et al., 2010). Of those who considered it conceivable, 75% stipulated that the person would have to be competent (de Boer et al., 2010). Similar proportions were found amongst GPs who had not performed assistance in dying for people with dementia; 45.1% (n=176) could imagine performing this in the future, while 47.9% (n=180) would always refer to colleagues or the Dutch Euthanasia Expertise Centre, and 7% (n=31) would never administer assistance in dying to people with dementia and would also never refer such people to colleagues (Schuurmans et al., 2020).

Support Needs

The anticipated support needs of GPs for assisted dying practices in people with dementia were higher than support asked for previously, and included wishes for increased input from Support and Consultation on Euthanasia in the Netherlands (SCEN) physicians, geriatric teams, palliative care teams, and the Dutch Euthanasia Expertise Centre (Schuurmans et al., 2020). Support from spiritual care providers, or moral deliberations, were less frequently requested (Schuurmans et al., 2020).

Most GPs (n=363; 85.8%) wanted to increase their knowledge on topics including; the law around assisted dying in dementia, assessing AEDs, communication skills, advance care planning, and the dementia trajectory

(Schuurmans et al., 2020). Most Canadian social workers (67%) requested further training on assisted dying (Bravo et al., 2022b).

Personal Factors

Religion

Several studies measured HCPs' religiosity, using either self-identification as religious, or a religiosity index. In two studies, it was not possible to extract the relationship between religion and attitudes towards assisted dying for HCPs who had, or were likely to have, experience working with people with dementia (Bolt et al., 2015; Brinkman-Stoppelenburg et al., 2020). A Swiss study of physicians did not find any significant association (Loizeau et al., 2019b). However, Canadian physicians scoring higher on a religiosity index held less favourable views on assisted dying in dementia (Bravo et al., 2022a). Canadian nurses who scored higher on religiosity indexes were also found to have less favourable views on assisted dying in end-stage dementia, based on written advance agreements (Bravo et al., 2018a).

In one Belgian study, 41% (n=46) of GPs described themselves as 'religious,': non-religious GPs were more willing to administer assisted deaths across all stages of dementia than religious GPs and were almost twice as likely to support legal adjustments to assisted dying than religious GPs (66% vs. 37%, $p<.001$). Religious GPs were more than twice as likely than non-religious GPs (39% vs. 18%, $p<.001$) to disagree with extending the conditions of AED to all patients, including those with dementia (Cleemput & Schoenmakers, 2019).

Disagreement that dementia could be a valid reason for life-ending practices in the presence of an AED was also higher amongst ECPs with a religious

background, as was inconceivability of administering assisted death to such people in the future (de Boer et al., 2010). However, this study did not illustrate how people with religious backgrounds were identified.

Age

Findings related to HCPs' age and attitudes towards assisted dying were mixed. One Canadian study found that older physicians were less agreeable with assisted dying in dementia (Bravo et al., 2022a). Potential legislative extensions on assisted dying in dementia were supported more by younger Belgian GPs than those aged ≥ 40 years (63% vs. 48%, $p < .005$); however, religion may have been a conflicting factor here, as most GPs who described themselves as 'religious' in this study were older (Cleemput & Schoenmakers, 2019). It is possible that younger HCPs have less clinical experience or are less aware of the complexities of assisted dying in dementia. However, in a Dutch study, ECPs who had not performed assisted deaths in people with dementia, but who considered it conceivable they may do so in the future, tended to be older ($t = 2.69$, $p = .007$; de Boer et al., 2010).

Personal Experiences

Bravo et al. (2018a) reported that nurses who found assisted death for incapacitated people with dementia acceptable were more likely to; have accompanied a dying friend or relative through the dying process (OR = 2.6, 95% CI: 1.05-65), make an assisted dying request themselves if diagnosed with dementia (OR = 8.8, 95% CI: 3.4-22.8), and ask a physician to carry out the advance assisted dying request of an incompetent relative (OR = 5.2, 95% CI: 2.1-13.3).

Qualitative Findings

Two studies gathered exclusively qualitative data (Coers et al., 2023; Schuurmans et al., 2019), whilst another four included qualitative data gathered from free-text comments (Cleemput & Schoenmakers, 2019; de Boer et al., 2011; Picard et al., 2019; Schuurmans et al., 2021). All data were gathered from studies based on physician samples across the Netherlands and Belgium. Four main themes emerged: challenges physicians faced, contextual factors, personal impact on physicians, and alternatives to assisted deaths.

Challenges Physicians Faced

Challenges faced when considering, consulting on, or performing assisted dying in people with dementia related to communication, family involvement, and societal influence.

Communication

Clear communication in advanced dementia was challenging where capacity for decision-making was lost. Two Belgian studies considered a proposed legislative extension to allow assisted dying in advanced dementia. In one, physicians in favour of and against this extension emphasised the need for the person to confirm their wishes (Picard et al., 2019); in the other, a much smaller proportion of GPs explicitly expressed feeling unable to support assisted dying if the person was unable to say 'yes' clearly (Cleemput & Schoenmakers, 2019).

In Dutch studies, physicians expressed that reciprocal communication was important for requests based on AEDs in advanced dementia, to decipher whether suffering was unbearable, confirm that assisted death was still the person's wish,

that the AED was valid, and to ensure the physician had a “*clear conscience*” (Coers et al., 2023; de Boer et al., 2011; Schuurmans et al., 2019).

For some physicians, inability to communicate with people would prevent them from accepting requests for assisted dying, or AEDs, on moral grounds (Schuurmans et al., 2019), with some reflecting that an assisted death in such circumstances felt “*secretive*” (Coers et al., 2023). Others noted the challenge of being restricted from discussing assisted dying by workplace policies (de Boer et al., 2011).

Family Involvement

Where reciprocal communication was no longer possible, physicians often relied on communication with family, which also presented challenges. Some GPs felt family should only be able to initiate assisted dying requests, or represent the person with dementia’s interests, if they were known to the GP, were involved in previous conversations about assisted dying, did not have conflicts of interests, were not pressuring the decision, and if the person had agreed to family involvement when they had capacity (Schuurmans et al., 2021). Other physicians felt it was important to consult family members and allow them to share opinions (Picard et al., 2019).

In a Belgian study, GPs explicitly said they would need the decision for assisted dying in advanced dementia to involve, and be shared with, relatives and carers (Cleemput & Schoenmakers, 2019). Others agreed that a consensual approach with family and other professionals could help to ensure the DCC were met (Coers et al., 2023), and that it was an appropriate time to perform an assisted death (Coers et al., 2023; Picard et al., 2019;). Others reflected that the final decision should always respect the patient’s wishes (Picard et al., 2019), with some

physicians recalling families being reluctant to consider assisted dying, despite an AED (de Boer et al., 2011). Conversely, other physicians spoke about feeling under pressure from family to perform an assisted death if they felt the person with dementia's life was undignified (Schuurmans et al., 2019).

Societal Influence

In two Dutch studies, physicians reflected on challenging societal ideas about assisted dying in dementia. Physicians suggested that societal ideas of dementia as an illness with little QoL, coupled with high value placed on autonomy (considered by some to be lost in dementia), could lead people to believe assisted death is a more dignified option (Schuurmans et al., 2019). Some physicians felt societal debate had been over-simplified (Coers et al., 2023) and that conflating assisted dying with a dignified death in dementia was problematic (Schuurmans et al., 2019). Others, however, spoke about feeling judged by society for performing assisted deaths (Schuurmans et al., 2019).

Contextual Factors

Contextual factors related to future suffering, legislation, and views on AEDs.

Future Suffering

In contrast to some quantitative studies, almost all Dutch physicians interviewed by Schuurmans and colleagues (2019) would accept a request for an assisted death from a competent person with early-stage dementia *if* they were convinced the person had – *or would soon have* – unbearable existential suffering. One participant remarked that people sometimes suffer more from “*suffering that is yet to come.*”

Legislation

Some physicians considered legislation vague, which made judging concepts like unbearable suffering and mental competence difficult; others felt the law and guidelines were clear (Schuurmans et al., 2019). Some physicians appreciated 'grey areas' of the law, which allowed for case-dependent decisions (Coers et al., 2023).

If Belgian legislation was extended, physicians commented on the conditions under which they would perform assisted dying in advanced dementia; ensuring the patient could confirm their choice, knowing the patient and their GP well, receiving confirmation from colleagues, and the patient's decisional capacity being evaluated by specialists (Picard et al., 2019). It was considered important to know the person, their life, and their life view very well (Cleemput & Schoenmakers, 2019).

Views on AEDs

Several Dutch studies found that physicians believed AEDs gave people false hope through misguided beliefs that their wishes for an assisted death would be followed (de Boer et al., 2011; Coers et al., 2023; Schuurmans et al., 2019).

Similarly, Belgian physicians reported a misperception that including wishes for an assisted death within an advance care plan gave people the right to this in advanced dementia (Picard et al., 2019). Some felt these misperceptions placed them under increased pressure to perform assisted deaths (Coers et al., 2023).

In practice, AEDs were not always followed, though some had a small effect on physicians' treatment decisions (de Boer et al., 2011). Some felt AEDs should be considered as discussion starters; building extensive medical records, advance care plans, and independent capacity assessments, were still necessary before assisting a person with dementia who no longer has capacity to die based on an AED (Coers

et al., 2023). Belgian physicians proposed that people should define, within advance agreements, their personal criteria for when an assisted death should be performed, which could support physician decision-making (Picard et al., 2019).

Personal Impact on Physicians

Many spoke about the emotional impact of performing assisted deaths. Some reported stress and poor sleep (Coers et al., 2023), while others experienced frustration, anger, moral distress, insecurity, and stress about technical issues with administration of the assisted death and the potential for legal consequences (Schuurmans et al., 2019). Some felt negative emotional impacts were alleviated when people, and families, expressed gratitude (Coers et al., 2023), while others spoke about feeling satisfaction, relief, and a sense of being in control, with one physician reporting a feeling of heroism after performing an assisted death (Schuurmans et al., 2019). Some physicians felt that the more experience a doctor gained of performing assisted deaths, the lesser the emotional impact, while others expressed concern that assisted dying should not become a physician's primary practice (Schuurmans et al., 2019). Physicians described managing the emotional impact of assisted dying by consulting and receiving support from other physicians (Schuurmans et al., 2019). However, some GPs felt these opportunities were limited, particularly in cases of advanced dementia (Coers et al., 2023).

Physicians also received support from their own families, while ECPs mentioned support from moral debates, spiritual caregivers, and psychologists; GPs appeared less aware of these support possibilities and expressed a need for support from spiritual caregivers (Schuurmans et al., 2019).

In two studies, physicians described personal reasons for refusal to perform assisted deaths in dementia: some cited religious beliefs (de Boer et al., 2011; Picard et al., 2019) or other personal dilemmas (de Boer et al., 2011). Others described outright refusal, not feeling able to do it, and the patient or family's choice, as reasons for referring requests to colleagues (Picard et al., 2019).

Alternatives to Assisted Dying

When discussing views and experiences of assisted dying in people with dementia, physicians reflected on potential alternatives to this practice. Some felt there was a lack of awareness of other end-of-life options and the normal dying process, and that more attention could be given to the importance of good end-of-life care (Coers et al., 2023). Although palliative care and natural death were presented as alternatives to assisted deaths (Schuurmans et al., 2019), palliative sedation was mentioned less frequently (Schuurmans et al., 2019), with some physicians describing this as a "*slippery slope*." (Coers et al., 2023). In one study, physicians suggested assisted suicide by a lay person be legalised (Schuurmans et al., 2019).

Discussion

This review aimed to provide a contemporary exploration of HCPs' attitudes towards, and experiences of, assisted dying in people with dementia.

In contrast to previous findings (Tomlinson & Stott, 2015), this review found that acceptability and support for assisted dying in dementia tended to increase as dementia progressed. However, across all stages of dementia, attitudes and experiences of HCPs were nuanced; differences were observed in jurisdictions where this practice was legal, as well as across disciplines, and were influenced by

clinical, professional, and personal factors. Challenges faced by HCPs, contextual factors, personal impact on physicians, and alternatives to assisted deaths in dementia were also considered.

Most HCPs disagreed with assisted dying in early-stage dementia. As people in early-stage dementia have the possibility of good QoL before the disease progresses; providing assistance in dying may be considered precipitous at this stage. Although some physicians reflected that people with early-stage dementia can suffer unbearably from the prospect of progressive dementia (Schuurmans et al., 2019), this viewpoint was not shared by all (Schuurmans et al., 2021; van Tol et al., 2010).

In advanced dementia, people had often lost capacity for decision-making. In the Netherlands, where assisted dying at this stage was permissible, people often completed AEDs. In jurisdictions where this was not legal, studies often included vignettes based on assisted dying requests, with and without advance agreements. These agreements appeared to have a considerable impact on HCPs' abstract decision-making, and conceivability of assisted dying in advanced dementia. In Canada and Belgium, HCPs showed stronger support for assisted dying in the presence of an advance agreement (Bravo et al., 2018a, 2018b, 2022b; Cleemput & Schoenmakers, 2019). However, in the Netherlands, where this practice is permissible, conceivability of assisted dying at this stage was much lower (Bolt et al., 2015; Brinkman-Stoppelenburg et al., 2020). This may be explained by Dutch physicians being more aware of the practical challenges of assisted dying in these cases.

Additionally, several studies mentioned misperceptions HCPs felt families and people with dementia had about AEDs (Coers et al., 2023; de Boer et al., 2011; Schuurmans et al., 2019). Despite AEDs being intended to communicate people's wishes when they no longer could themselves, in practice, HCPs were reluctant to use them in this way. Instead, it appeared they were used to support restricted treatment pathways, rather than assisted dying, as dementia progressed (de Boer et al., 2011).

Adherence to AEDs could be morally complicated by HCPs not feeling comfortable to enact them when unable to communicate and confirm that people's previous desire for an assisted death align with current wishes (Cleemput & Schoenmkaers, 2019; Picard et al., 2019; Schuurmans et al., 2019). Without clear communication, HCPs may feel a greater sense of moral and emotional responsibility, that is not present with other assisted dying requests. This may also be influenced by the possibility that people, when writing these agreements, considered their future suffering would be unbearable, but may experience periods where they lack insight, which makes it challenging to determine QoL and degree of suffering.

In end-stage dementia, acceptability and support for assisted dying amongst HCPs was highest, particularly when advance written agreements were present (Bravo et al., 2018a, 2018b, 2022b; Cleemput & Schoenmakers, 2019). Acceptability of assisted dying at this stage aligned with assisted dying in end-stage cancer in Canada (Bravo et al., 2018a, 2018b, 2022b); however, in the Netherlands, this was not the case (Bolt et al., 2015). In Canada, the concept of assisted dying in end-stage dementia may feel more acceptable to HCPs, as it is comparable with end-stage physical illnesses (where assisted dying is legal). Whereas in the Netherlands,

it is possible that again HCPs were influenced by whether the DCC of unbearable suffering could be met in end-stage dementia. Canadian HCPs' attitudes may also have been influenced by descriptions given in clinical vignettes; Bravo and colleagues (2018a, 2018b, 2022b) notably described the person with dementia as *distressed* at the end-stage, compared to being comfortable in advanced-stage dementia. It is possible that the depiction of distress had a stronger influence on attitudes than the progression of dementia.

This review also indicated differences in agreement and acceptability of assisted dying in dementia across different disciplines, which could be attributed to professionals' level of involvement, or distance, from the process of providing assistance in dying. Social workers, potentially the furthest removed from the procedure, showed highest acceptance and support (Bravo et al., 2022b), followed by nurses (Bravo et al., 2018a), and, lastly, physicians. It was physicians, often most directly involved and holding most responsibility, who tended to have the lowest levels of agreement and acceptability of assisted dying in dementia (Bravo et al., 2018b). Further research would be helpful to draw fuller conclusions from this.

Compared to other physicians, GPs found the idea of administering assisted deaths in advanced dementia more conceivable (Bolt et al., 2015; Brinkman-Stoppelenburg et al., 2020) and were more likely to administer this themselves if it was their own patient (Bravo et al., 2018b). Considering that GPs tend to have longer relationships, and more familiarity with people, they may feel more assured that assistance in dying is aligned with the person's values and wishes, and hence may feel more confident to enact this.

Religion, age, and personal experiences were amongst other factors which may influence HCPs' views and experiences of assisted dying in dementia. Religious HCPs tended towards less favourable views than non-religious HCPs, which is consistent with previous systematic reviews findings (Chakraborty et al., 2017; Tomlinson & Stott, 2015). The picture regarding age was less clear and requires further investigation.

Although only two studies referenced the noted Dutch legal case (Schuurmans et al., 2020, 2021), it is possible that this influenced attitudes of HCPs towards assisted dying more broadly than was mentioned, particularly as the outcome of the case was unknown when most studies were completed.

However, given that several studies included in this review reported low to moderate response rates, the findings should be interpreted cautiously.

Limitations

The review was limited to English-language studies, which may have excluded research in a broader range of countries. The narrow range of countries and professionals included, as well as including studies drawn from the same samples (reporting different data), means that results must be interpreted cautiously and may limit generalisability.

Studies by Schuurmans and colleagues (2019) and Coers and colleagues (2023) may have drawn on similar samples; eliciting participants as part of Dutch national newspaper responses to the 2018 prosecution of a physician. This may mean the views of these HCPs were over-represented, however, as these studies were completed at different time points, it is possible their views had changed.

There were also some limitations within studies included in the review. The response rates of several survey studies were low, which may have created a sampling bias and may indicate a high risk of non-response bias.

Standardised questionnaires on attitudes towards assisted dying in dementia were not used in included studies; however, several questionnaires were devised based on literature reviews and previous research, in addition to being tested and revised by expert panels. While the use of clinical vignettes has been considered helpful in understanding how HCPs make decisions, it has also been argued that vignettes can simplify complex situations (Evans et al., 2015). Decisions in practice may be based on more information and take place over an extended period of time. Finally, most studies included were from jurisdictions where assisted dying is legal, which may indicate that it is more challenging to elicit HCPs' views on assisted dying in dementia, in countries where this is illegal – including the UK.

Clinical Implications

Given the emotional impact and burden of responsibility felt by HCPs in making decisions about assisted dying in dementia, further opportunities for psychological support should be explored. In countries where this practice is legal, HCPs also requested further training in assessing AEDs, the law around assisted dying in dementia, communication skills, advance plans, and the dementia trajectory (Schuurmans et al., 2020). Providing this training could improve HCPs' confidence and assuredness in decision-making around assisted dying in dementia.

The review suggested that AEDs are rarely enacted for people with advanced dementia, but it is unclear whether this is something people or families are aware of, when they write them. Assisted dying review committees, and local and national

governments, should help to raise awareness of AEDs, their limitations, and potential implications, which could lessen the pressure felt by HCPs to adhere to these directives. It may be challenging to have to explain their non-adherence to people with dementia and their families.

Additionally, awareness-raising campaigns could be undertaken to promote more positive social dialogues about dementia, and to lessen the stigma around this diagnosis, which underlies some peoples' fears and wishes for assisted deaths.

Conclusion

This review considers evidence from jurisdictions where assisted dying in dementia is legal, as well as those where it is not. HCPs' views and attitudes towards this practice appeared to be largely context dependent; with increasing acceptance of assisted dying as the person's dementia progresses in the presence of advance written agreements. However, there are clear areas of concern for HCPs, such as being unable to communicate with people, misperceptions surrounding AEDs, and difficulty ascertaining people's level of suffering, which influence their opinions on assisted dying and can make experiences of this practice more complex and emotionally demanding.

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Chapter Two

Empirical Paper

**“With one hand tied behind your back”: Experiences of mental health nurses
working with people with Young Onset Dementia in the UK**

“With one hand tied behind your back”: Experiences of mental health nurses working
with people with Young Onset Dementia in the UK

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Abstract

Aim: Little is currently known about the experiences of nurses working with younger adults diagnosed with dementia. This study aimed to explore the lived experiences of Young Onset Dementia nurses in the UK.

Design: The study used a cross-sectional qualitative design; Interpretative Phenomenological Analysis.

Methods: Semi-structured interviews were undertaken with eight mental health nurses working with people with Young Onset Dementia.

Results: Participants reflected on the tensions between their personal and professional lives, the systemic challenges they faced in their role, and the unique aspects of working as Young Onset Dementia nurses.

Conclusion: Participants spoke about the challenges, rewards, and emotional impact of their work, as well as frustrations at systemic barriers they faced. Clinical implications are discussed, as well as ideas for further research in this area.

Implications for the Profession and/or Patient Care: This study offered suggestions for how mental health nurses working in this area could be better supported through regular clinical and peer supervision. Improving support offered to staff may also improve the care nurses are able to offer people with Young Onset Dementia and their families.

Impact: The study will impact on nurses working with people with Young Onset Dementia, their managers, and those in senior leadership roles.

Patient or Public Contribution: No patient or public contribution.

Keywords: Young onset dementia; mental health nurses; experiences; qualitative

What does this paper contribute to the wider global clinical community?

- A better understanding of the lived experiences of a sample of mental health nurses working with people with Young Onset Dementia in the UK.
- Suggestions for how to improve staff support, and consequently patient care, in this clinical population.

Introduction

In 2013, it was estimated that there were approximately 42,325 people in the UK living with young onset dementia (YOD) – defined as dementia diagnosed before the age of 65 years (Prince et al., 2014). These numbers are expected to rise significantly over coming years (Carter et al., 2018), making the provision of health and social care services to meet the needs of younger people with dementia, a priority. It is already well-established that the needs of people with YOD differ from older cohorts (Giebel et al., 2020), related to both the range of clinical presentations and distinctive psychosocial issues unique to younger populations.

Background

Clinical Presentations

Younger adults tend to experience a broader range of dementia diagnoses, with one in three cases linked to a rarer underlying cause (Royal College of Psychiatrists [RCP], 2018). Differences in subtypes mean there are also differences in presentation, with a greater proportion of non-amnestic dementias in younger cohorts (RCP, 2018). There can also be marked differences *within* subtypes. For example, whilst Alzheimer's Disease primarily presents with deficits in episodic memory in older adults, it is more common to see difficulties with executive function, visuospatial abilities, and apraxia in younger people (Tellechea et al., 2018). These differences can make it difficult to assess and diagnose younger adults, who consequently experience higher rates of misdiagnosis (Carter et al., 2018) and longer routes to diagnosis compared to older adults (van Vliet et al., 2013).

Psychosocial Issues

Having dementia at a younger age has several potentially unique implications for the individual and their family, which may include loss of employment, changes in family roles, shifts in self-worth and identity, and reduced opportunities for independence (Cartwright et al., 2021; Clemerson et al., 2014). Younger adults are more likely to have dependent children, as well as older parents who may require support (Chirico et al., 2022). Family members, including partners and children, may need to take on caring roles and may consequently experience changes in relationships, carer burden and stress (van Vliet et al., 2010). Younger carers – when compared to older caregivers – report higher levels of psychological distress, especially related to difficulty coping with behavioural and psychological aspects of dementia (Arai et al., 2007; Svanberg et al., 2011). This may increase the need for formal support from services, including from nurses and other healthcare professionals.

Young Onset Dementia Nursing

The YOD nurse role is a relatively new development, and involves various tasks, such as; managing neuropsychiatric symptoms associated with YOD, offering patients and families counselling, visiting people in their homes and completing risk assessments, liaising with other health and social care services and advocating on behalf of people with YOD and their families (Spreadbury & Kipps, 2018). In addition to assessing and reviewing cognitive difficulties, YOD nurses may also need to monitor; mood and personality changes in people with YOD, the impact of any medication changes, behaviours that challenge, and any difficulties people with YOD experience in relation to other daily activities, such as eating and sleeping

(Spreadbury & Kipps, 2020). These nurses may also be tasked with offering support to younger people and their families who encounter challenges with interpersonal relationships, caregiving stress, parenting, finances, and employment as the dementia progresses (Spreadbury & Kipps, 2020). The YOD nurse may also need to initiate conversations with people with YOD and their families about planning for the future, which may include discussions around wills, power of attorney and driving, as well as the potential later need for residential or end-of-life care. Thus, the role of the YOD nurse is complex, given its need to address the diversity of clinical presentations seen in younger adults, the psychosocial implications of the diagnosis, the likelihood of combined mental and physical nursing needs as the disease progresses and of encountering caregiver burden and stress (Spreadbury & Kipps, 2020). The role of the YOD nurse is likely to vary across the UK, depending on the local support services and resources available, as well as the capacity and workload of each individual YOD nurse. Indeed, YOD nurses in the UK often need to work across the boundaries of different health and social care localities, covering a wide geographical area, which can create challenges with resourcing these roles (Spreadbury & Kipps, 2020).

The service context in which YOD nurses operate may add to the complexity of the role, as YOD nurses are often based within older adult dementia care services. Indeed, most dementia services are structured around the needs of older people (Carter et al., 2018), with a lack of age-appropriate services offered to younger adults. Previous research has highlighted the frustration experienced by healthcare professionals when supporting people with YOD, given the lack of appropriate services available (Kilty et al., 2019).

The progressive nature of dementia means that YOD nurses will likely continue to support younger people, and their families, as they approach end of life. Research in other areas of healthcare highlights the challenges experienced by nurses working in this context, which can bring them into contact with the fragility of health and remind them of their own mortality (Ingebretsen & Sagbakken, 2016). Research indicates the need for staff to receive substantial support and professional supervision when working clinically with people approaching the end of their lives (Renzenbrink, 2005); however, it is unclear whether this support is routinely available to YOD nurses. Indeed, there is little known about the infrastructure needed to support YOD nurses.

Although YOD nurses' caseloads may be smaller than those of colleagues working with older cohorts, the work is often more complex and potentially more emotionally demanding (Spreadbury & Kipps, 2020), which may result in higher rates of compassion fatigue, burnout, and staff turnover.

The Study

Rationale

Previous research has explored the experiences of nurses and other healthcare professionals' working with dementia across the lifespan (Houghton et al., 2016; Monthaisong, 2018), alongside their views on YOD service delivery within Canadian (Ducharme et al., 2014), Irish (Kilty et al., 2019) and Italian (Ottoboni et al., 2021) contexts. Research by Ducharme and colleagues (2014) found that healthcare professionals often identified with the difficulties experienced by people with YOD and their families, who were of similar ages to the professionals

themselves. They also reported a sense of powerlessness related to the gap in services and resources available to this population and suggested some ideas for more systemic approaches to YOD care, whereby the needs of the family as a whole are considered and supported, as well as a desire for further training to be made available to healthcare professionals to enable them to better support the YOD population (Ducharme et al., 2014).

Similar themes emerged from an Irish study of healthcare professionals working with people with YOD, where concerns were also reported about the lack of age-appropriate services for younger adults with dementia, and the moral challenge this presented for professionals (Kilty et al., 2019). Healthcare professionals acknowledged a sense of frustration when they were unable to direct people with YOD to appropriate support and resources, as the dementia-specific services available were aimed at older adults, specifically those over the age of 65 (Kilty et al., 2019). Professionals also reflected on the emotional impact of working with, and supporting, younger people and their families experiencing what they described as “*emotional living grief*” as a result of the progressive nature of YOD (Kilty et al., 2019).

In an Italian context, healthcare professionals reported the difficulties they experienced with delays in diagnosis of YOD and heavy workloads, which prevented them forming closer relationships with the people they supported (Ottoboni et al., 2021). They, too, spoke about the lack of age-appropriate services to direct people with YOD towards, and in particular, reflected on the need for people with YOD and their families to be able to access counselling services and respite care (Ottoboni et al., 2021). They described the need for further guidelines, knowledge and specific education and training on YOD amongst both professionals

and public, and also reflected on the need for staff support for professionals working with people with YOD, whose lives often mirrored those of the people they supported (Ottoboni et al., 2021). The healthcare professionals included in this study also proposed ideas for service improvement for people with YOD which included; linking in with non-statutory services to develop more supportive and meaningful activities targeted at younger people with dementia and their families, and encouraging advance care planning and decision-making for the future (Ottoboni et al., 2021).

These studies report concerns about the responsiveness of services, gaps in service provision, the extent of knowledge on YOD, the impact of supporting people with YOD on staff, as well as ideas for future service developments. However, whilst nurses were included in these studies (Ducharme et al., 2014; Kilty et al., 2019; Ottoboni et al., 2021), the experiences of YOD nurses specifically were not explored in-depth and there was no direct consideration of YOD care within a UK setting.

Research in the UK and Ireland has indicated that the concept of specialist YOD nurses is highly valued by staff (Kilty et al., 2019; Spreadbury & Kipps, 2020). However, the roles are relatively rare, and can be considered precarious when services are under-resourced (Spreadbury & Kipps, 2020). The need for a greater understanding of the YOD nurse role, at this time of expansion, is significant. Understanding more about their lived experiences may help services develop strategies to support their work and promote their wellbeing, which in turn may enhance care for the YOD population and increase staff retention.

Aim

This study aimed to explore the experiences of nurses with current or previous experience working with people with YOD in the UK. People currently working in these roles were included to provide insight into what it is like to work with this population at this time, while people who previously worked in the role were included to explore past experiences and any reasons nurses may leave the role. It was intended to explore factors relating to the professional nature of the nurses' roles, such as clinical supervision and peer support, as well as personal factors, such as the emotional impact of working with younger people with dementia and their families.

Method

Design and Theoretical Framework

An exploratory cross-sectional design was used to explore nurses' experiences of working with people with YOD. Interpretative phenomenological analysis (IPA) was chosen as the framework for the study, as it focuses on how people interpret and make sense of their lived experiences (Smith et al., 2022), in this case, of working with people with YOD. This approach draws on the principles of *phenomenology*, exploring experiences, *hermeneutics*, focusing on the meaning of these experiences for both participant and researcher, and *idiography*, ensuring the overall findings represent the experiences of each individual, whilst also reflecting the shared and unique experiences within the wider sample. (Smith, 2017). As per IPA tradition, analysis aimed to establish an understanding of participant's *subjective* experiences of nursing in the context of YOD. Rather than seeking to establish a

definitive or generalisable account, the study aimed to highlight features of experience deemed important to the individuals who took part.

Ethical Considerations

The study received ethical approval from Bangor University School of Human and Behavioural Sciences Ethics Committee (Ref 17212; Appendix A).

Recruitment

Information about the study, including how to express interest in participating, was shared via professional bodies (e.g., Association of Clinical Psychology – UK), clinical networks, and third-sector organisations (e.g., Young Dementia Network). Some participants were also recruited through additional convenience and snowball sampling as recruitment materials were disseminated amongst teams. Those who contacted the researcher via email to express interest in participating were provided with a written participant information sheet (Appendix B) and given time to read this and ask any questions. Those wishing to participate returned a signed electronic consent form (Appendix C). Verbal consent was also gained prior to each interview. Over the recruitment period, 13 people expressed an interest in participating: the first 10 participants were approached and eight consented to take part. The number of participants is consistent with the recommended sample size for IPA research (Smith et al., 2022).

Inclusion and Exclusion Criteria

In line with IPA principles, a small purposive sample was recruited using specific inclusion and exclusion criteria (see Table 1).

Table 1*Inclusion and Exclusion Criteria*

Inclusion Criteria	Exclusion Criteria
-Adults aged ≥ 18 years	-Non-English-speaking participants.
-Currently or previously working professionally as a qualified nurse in the UK.	-Nurses working with YOD in services with additional specialisation (e.g., learning disabilities services).
-Having worked either in a specific YOD nurse role for a minimum of six months – currently or at another time within the past 10 years OR having worked in a generic older adult nurse role with specific involvement with people with YOD for a minimum of six months - currently or at another time within the past 10 years	

Data Collection

All participants were interviewed by the first author, a trainee clinical psychologist, and informed that the research contributed towards a professional qualification. Participants were offered interviews via telephone or online videoconferencing (Microsoft Teams). Five participants chose to be interviewed online, and three were interviewed via telephone.

Brief demographic information was gathered from participants at the start of interviews. This included age, gender, current clinical role, whether they were working with people with YOD currently, total length of time working with people with YOD, and total length of time qualified and employed as a nurse.

Interviews were semi-structured, and an interview guide was used flexibly, with questions exploring what it was like to work with individuals with YOD, challenges and rewards of this work, whether YOD work impacted on participants' personal lives, if participants felt prepared for working with this population, and whether they felt supported by colleagues and managers (Appendix D). Field notes were made directly after interviews and included the researcher's initial observations, thoughts, and reflections.

Interviews lasted between 52 and 86 minutes and were audio- or video-recorded to enable transcription. Each participant was sent a £20 online voucher to thank them for participation. Each participant was also given a debrief sheet, which included information if they needed further support after the interviews (Appendix E).

Data Analysis

Interviews were transcribed verbatim and anonymised. Pseudonyms were provided to help position the analysis within participants' lived experiences (Smith et al., 2022). Data were analysed in accordance with contemporary IPA guidelines (Smith et al., 2022). Each transcript was read several times by the first author to become familiar with, and actively engage with, the data. Exploratory notes were then written in the right-hand margin of each transcript, identifying anything of interest in the way the participant talked about and understood their experiences of working with people with YOD. These exploratory notes were examined further to develop experiential statements, which were noted in the left-hand margin of each transcript (Appendix F). This stage represented a movement from focusing on the transcript as a whole, to focusing on the exploratory notes and related transcript segments. This part of the analysis involved more of the researcher's perspective,

whilst remaining closely tied to the participant's lived experiences. Next, the experiential statements were analysed for connections between them (Appendix G), and personal experiential themes were drawn from the cluster of connections between statements. This process was repeated for each transcript, with care taken to ensure the personal experiential themes reflected each individual participants' experiences. The personal experiential themes were searched for patterns of similarity and difference. These were then used to create group experiential themes to demonstrate the shared and unique experiences of the participants. Initially, there was some overlap between group experiential themes; following discussion between authors, these were revised to capture participants' experiences more distinctly.

Reflexivity and Rigor

I am a female in my early 30s training to become a Clinical Psychologist. Prior to training, I had worked in older adult settings, and was aware of nurses and other professionals working with the YOD population and some of the systemic challenges they faced. I do not have direct experience of working with this population myself. I have familial experience of dementia, as my grandmother received this diagnosis later in life, thus I have some awareness of the impact dementia can have on families. I do not have any personal experience of YOD.

Some participants were recruited through professional links to the authors. As such, I was mindful they may have felt drawn to give a 'right answer' during interviews. However, I felt participants were open and detailed in their discussions of their experiences of their roles.

The study aimed to adhere to the four principles of quality for qualitative research, outlined by Yardley (2000; 2008): *sensitivity to context, commitment and*

rigour, transparency and coherence, and impact and importance, and the IPA-specific quality indicators outlined by Nizza et al. (2021): *constructing a compelling unfolding narrative, developing a vigorous experiential, and/or existential account, close analytic reading of participant's words, and attending to convergence and divergence*. Transcripts, personal experiential themes, and group experiential themes were reviewed and discussed with the second and third authors to ensure analysis remained grounded in the participant's experiences and represented a credible interpretation of the data. Group experiential themes are presented in a narrative account that includes verbatim quotes; these are embedded to promote transparency, evidencing how interpretations relate to the data.

Findings

Participant Characteristics

All participants were female, with ages ranging from 35 – 60 years ($M = 49.1$, $SD = 9.7$). Five participants worked, or had previously worked, with people with YOD in Wales, two participants worked with people with YOD in North West England, and one worked with people with YOD in the West Midlands of England. The participants had been qualified and employed as nurses for a range of 10 – 42 years ($M = 26.4$, $SD = 14.01$). Participants had worked with people with YOD for between 1 and 20 years, with an average of 7.5 years' experience working with people with YOD ($SD = 7.03$).

The types of services participants worked in varied; one participant worked in a service specifically focused on rare dementias including YOD, five participants worked, or had previously worked, in a 'virtual young onset dementia service' (a service within the same Trust/Health Board, but covering different geographical

areas) however day-to-day, these participants were based separately within older adult teams. The remaining two participants also worked within older adult mental health services. One participant was involved in the assessment of YOD and later post-diagnostic input and support, while the remaining seven participants supported people after they had received a diagnosis of YOD and were not involved in the assessment process. Three participants had retired and returned to work part-time, one participant worked part-time in YOD and part-time in an older adult mental health team, while four participants worked full-time, though two of these reported their roles occasionally involved working with people with diagnoses other than YOD, e.g., supporting crises in older adult teams. All but one participant was working with people with YOD at the time of interview.

Study Findings

This study aimed to explore the experiences of nurses working with people with YOD in the UK. Although there were commonalities in some of these experiences, there were also some unique differences. The analysis generated three group experiential themes, within each were several subthemes. A summary of these is displayed in Table 2 below.

Table 2*Summary of Group Experiential Themes and Subthemes*

Theme	Subtheme	Overview of Theme
1. Tensions between personal and professional lives	<ul style="list-style-type: none">- Blurred boundaries of close relationships- Impact of personal experience of YOD on professional life- Personal resonance of the role- Impact on home life	Describes the overlapping of the participants' personal and professional lives, and the impact this has on them both emotionally and within their clinical roles.
2. Systemic challenges faced by YOD nurses	<ul style="list-style-type: none">- Professional loneliness- Availability of support- Battle for recognition	Focuses on the systemic challenges faced by participants, which increased the sense of individual responsibility they felt to support people with YOD, and the pressure to advocate for their own clinical roles.
3. Unique aspects of YOD nurse role	<ul style="list-style-type: none">- Supporting families at a life stage when dementia is not expected- Emotional impact of supporting younger adults' end-of-life care- 'Specialist' but not	Identifies aspects of YOD nursing which separates it from other dementia nursing roles, including the emotional impact of supporting younger adults and their families experiencing a life-limiting diagnosis and participants' conflicting feelings about being referred to as 'specialist' YOD nurses.

The following transcription conventions were used:

... Material omitted to shorten quote.

Underlined Participant emphasised this word.

[] Explanatory information/non-verbal communication provided by author.

1.Tensions Between Personal and Professional Lives

Each participant described times they experienced tensions between their personal and professional lives, and the roles they occupied in each of these spheres. The tensions between the personal and professional aspects of their lives were at times emotionally evocative for participants, and presented them with complex ethical and moral dilemmas.

Blurred Boundaries of Close Relationships

The length of nurses' involvement with people with YOD and their families meant they developed close relationships and were sometimes described as akin to family. As Hannah recalled of one carer: *"he actually said to me eh, 'You've been like a second daughter' [smiles]"*. Some participants felt this closeness allowed them to provide better care; however, Laura described it as a *"double-edged sword"* which risked families becoming overly reliant on the YOD nurse for support. This seemed to place an additional responsibility on them, to be as reliable, and available to offer support, as a family member.

This sense of responsibility did not appear to lessen when relationships ended, either through the person with YOD's admission to residential care or

following death. Hannah described a sense of helplessness at being “*taken away*” from people at an emotionally challenging time. She explained:

You don't wanna seem like you... don't care anymore cause it's not that you don't care. It's just that there's no role for you... so that's the difficulty ... the relationship that you have had and they...feel like you've... given up.

Ending relationships with families she had built a close relationship with evoked guilt in Hannah, who worried that families would perceive she had abandoned them. There also seemed to be an internal conflict for nurses who did not necessarily want to end these relationships, but who were obliged to because of service restrictions.

When these relationships ended, there was also a sense of grief for some nurses. Emma reflected, “*that's sad again, isn't it? ... when you don't have to go into that home anymore... Suddenly you're in somebody's life and then suddenly you're not.*” For these YOD nurses, there was often an abrupt and unnatural end to a real relationship, which created a sense of disenfranchised grief.

Impact of Personal Experience of YOD on Professional Life

Two participants reported familial experiences of YOD, while a third described a family experience of dementia just beyond the threshold of YOD. All three described how family members' experiences influenced their professional lives. Anna recalled her family member's early symptoms were dismissed, with support post-diagnosis being poor, which motivated her to improve care for other people. Although via different circumstances, Hannah too appeared motivated to work with YOD because of a family experience of the diagnosis, lack of information provided to her family about YOD, and the absence of local support. Familial experiences provided a powerful motivation for

these nurses to improve YOD care for other families, and to provide for them the care they wished their own family members had received.

Vanessa described the difficulty of juggling her role as a YOD nurse with caring for a parent with dementia simultaneously:

That was really hard because it was in the same area that I was working and he ended up having to go into a care home where I was going in... I always had empathy with people, but it just gives you that little bit more understanding about what people are... truly going through... from a personal point of view... caring for someone with dementia is really, really hard.

Vanessa's lived experience granted her a greater appreciation of the challenges faced by familial carers of YOD and may also have provided her with greater insight into the support she could offer in her professional role, based on the support she would have valued as a carer.

Personal Resonance of the Role

Working with people of similar ages prompted nurses to consider how they would cope with YOD and reminded them of the fragility of their own health. Vanessa explained: *"Being very similar in age... you can't help but walk away and think [slight smile, widens eyes] 'God you know, that could be me, that could be any of my family.' "* This peer-like relationship led several participants to compare their lives to those they supported, which evoked feelings of sadness and guilt when they acknowledged feeling lucky in comparison. Conversely, Melanie reflected that these comparisons encouraged her be more proactive in her own life, *"It's given me the kind of catapult to 'Right we need to start now' not wait a few years."* Working with people they could identify with prompted these YOD nurses to reflect on the

unpredictable nature of life and their own mortality, factors which contributed to the emotional intensity of the role.

Two participants noted the personal impact of supporting people who expressed wishes for assisted deaths when their dementia progressed. Hannah explained:

I was really, really anxious about going to see the patient... I was thinking, half of me gets why they would wanna do it, but the other half doesn't and it was like a bit of a turmoil in my own... brain, so imagine how they must be feeling.

For Anna too, the emotive nature of this topic was evident, and she became tearful while recalling her conversation with a person with YOD and their spouse, who they had asked for support “*when the time comes.*” Navigating conversations around assisted dying may have been particularly emotionally confronting for these participants who had familial experiences of YOD, but these conversations could also present a challenging moral situation: YOD nurses may simultaneously feel empathy and a pull to give the ‘right response’ *and* a responsibility to encourage people to think differently given the illegality of assisted dying in the UK.

Despite the emotional impact of the role, participants were unanimous in the importance of protecting families from *their* emotions. Claire explained:

It's difficult because you're trying to... support that person... And try and [sighs] not cover your own feelings, but obviously dampen them down a bit, because the last thing you want to do is stress them out even more [slight laugh] with... your own sort of feelings.

There appeared to be an implied cultural importance within nursing, of concealing internal responses to emotionally evocative situations, whilst outwardly appearing professional and calm – as Claire described it, having “*your nurse hat on.*”

Impact on Home Life

Participants spoke about the challenge of leaving the people they support behind at the end of the working day. For Rachel, her likelihood of having “*sleepless nights*” was increased by feeling powerless to completely mitigate the risks YOD presented to people’s safety whilst being cared for at home. Participants described sometimes being less available to their own families because they were either preoccupied by, or felt emotionally depleted by, their roles.

You’re not just a nurse, are you? You’re...a mother, you’re a sister, you’re a daughter, you’re a...wife... And it kind of impacts you emotionally with them. Because sometimes, y’know, they want you to provide emotional support, um and if you’re a bit worn-out, if you’re a bit weary, y’know, you find that hard... you’re like “Please, not now.” (Laura)

Vanessa echoed Laura’s sentiments of sometimes not wanting to speak to family members “*until just had a bit of headspace*” to process the emotional impact of the working day. Both recognised the competing demands of personal and professional responsibilities, and the emotional toll it took on them when they were prevented from being fully present in their home lives.

Emma and Hannah described times they felt drawn to offer families support outside of working hours, but attributed this to an understanding that people would not reach out for support unless it was needed. Hannah recalled:

He [carer] was having feelings of guilt... So it was like Saturday night and I'm on the phone [smiles] and me husband and... the kids are in the other room and they're like, "What are you doing in work?" and... I'm like, "Just leave me alone for five minutes, I just need to make sure that this person's okay".

These YOD nurses may feel compelled to offer support outside of working hours because of their close relationships with families and empathic awareness of the difficulties they faced. There was also a sense that, for some participants, offering this support allowed them to feel more relaxed whilst away from work, which was perhaps reinforced by cultural and societal ideas about 'good' nursing care, where nurses go above and beyond to support people, even if this means offering support outside of their working hours. While some reflected on the challenge of separating work and home life, Melanie felt her ability to do this had improved with time, *"it's something you learn to do."*

2. Systemic Challenges Faced by YOD Nurses

Participants spoke about the systemic challenges they faced; which often resulted in them feeling an increased individual sense of responsibility for their own wellbeing, as well as that of the people with YOD and the families they supported.

Professional Loneliness

Several participants described their role as lonely. This feeling was intensified by being embedded in older adult teams, where colleagues often had access to more external support. Anna explained:

Sometimes you do feel like you're on your own [pauses]. Because I'm in amongst a team primarily deal with older persons... they've usually got... social care involved or they're in a care home... whereas my patients, they're

adults living in the community only with their spouse or sometimes on their own [slight laugh]... it does make you worry and I always feel like I have to be one ahead of myself... making sure that...everyone is safe.

Being the only YOD nurse amplified the sense of individual responsibility that Anna and other participants felt. The weight of this generated a persistent uneasy feeling that they needed to be alert and prepared for all eventualities to keep the people they supported safe.

Participants spoke about the emotional impact the lack of resources for the YOD population had on them, when they were unable to signpost people with YOD and their families to external support. Vanessa explained:

That made you feel a bit lousy, y'know thinking well I wish there was more things out there... you felt useless really, you felt inadequate yourself sometimes that y- you weren't able to find that that place or y'know find that help for them.

Explaining this lack of resources to families led some nurses to internalise a sense of being “*inadequate*” or “*useless*” in their roles. Laura felt this lack of resources prevented her from doing her job properly, “*You want to be able to, well I do [laughs] I want to give them everything! And you can't. You know, you feel as if you're doing it with one hand tied behind your back.*” This description of feeling as though she was working with one hand tied behind her back highlighted the sense Laura, and other participants, had of being constrained in the support they could offer, by the lack of support and resources available for the YOD population, and their feeling of helplessness to be able to alter this.

Melanie recalled the feeling of sadness and resignation she experienced when one of her younger patients was admitted to a nursing home for older adults. There was a sense that directing younger adults towards services designed for older adults went against what YOD nurses believed would be best for them; however, they were powerless to offer a more appropriate solution. It also highlighted the importance for these participants of being able to do their best for people, and the discomfort they felt when prevented from doing this because of circumstances beyond their control.

The lack of YOD-specific resources encouraged many of the nurses to create resources within their own services, such as peer-support groups, carer-support groups, and WhatsApp groups, to help facilitate peer connections between people with YOD and their families.

Several participants cited the creation and facilitation of these groups as the most rewarding aspects of their role. Emma and Rachel both reflected that seeing support and friendships *“blossom”* amongst people in groups they facilitated was rewarding, *“that gives me a buzz”* (Emma). Hannah and Melanie added that seeing visible changes in people with YOD after attending groups and gaining confidence, was rewarding, *“it makes me smile that we’ve been able to do that for somebody”* (Hannah). Some participants spoke about adapting interventions targeted at older adults with dementia for YOD populations, such as Cognitive Stimulation Therapy (Spector et al., 2001), while Rachel spoke about utilising social care interventions, which were not targeted at this population, but which seemed appropriate.

There was a sense throughout that the YOD nurse role required creativity to support the needs of this population. Despite the challenges of the lack of resources

to signpost people with YOD towards, it seemed participants felt a sense of pride and reward in creating and facilitating YOD groups within their services.

Availability of Support

The level of support participants received from colleagues and senior management varied, and influenced how they managed the challenges of the role. Claire reflected that having peer and managerial support allowed her to cope with stresses. Rachel echoed this and suggested that sharing decision-making with colleagues helped to mitigate uncertainty. Availability of peer-supervision, clinical supervision, and reflective spaces varied. Some participants valued these opportunities, suggesting that peer support was a crucial aspect of YOD nursing because of the uniqueness of the role. Emma explained:

The peer-support group... that's been really useful... it is really, really important that we support each other, isn't it? Because it is unique, it is different... we work with people with really unusual dementia sometimes... so that... takes its toll ... So it's really, really important.

Peer-support appeared important for both the emotional aspect of the role and for sharing knowledge when working with more unusual YOD subtypes. Emma also reflected on YOD nurses who were prevented from accessing peer-support by management later leaving the role. She wondered whether this had influenced their decisions. Providing a reflective, supportive space seemed to be an important aspect of staff retention, but was not readily available for all the participants.

Others felt there were barriers, such as working part-time, ill-timed supervision or reflective spaces, and lengthy distances to travel, which prevented them

accessing, or fully benefitting from, these support structures. If supervision groups happened infrequently, nurses had often moved on from the difficulty they were experiencing, and felt these groups were not responsive enough to meet their needs.

Barriers to accessing support, and a sense of professional loneliness are likely to increase the sense of individual responsibility and potential frustration felt by YOD nurses. Without regular peer or professional support, YOD nurses may miss opportunities to experience normalising peer-conversations and to feel a sense of community with peers.

Battle for Recognition

Frustration at the lack of awareness of the YOD nurse role amongst senior management was a connecting thread across accounts. Anna explained, *“justifying my role...has been the major battle ...with... SLT [Senior Leadership Team]... Basically not focusing on young onset... ..I feel like I always have to argue and advocate my case...it's... very apparent that there's lack of understanding.”*

The language used by Anna, having to *“justify”*, *“battle”*, and *“argue,”* was echoed by others, evoking powerful images of the struggle some participants faced in achieving recognition for their role. Vanessa, too, felt she had to canvass senior management, describing *“constant pushing all the time,”* to draw attention to the significance of the work. Participants struggled to maintain motivation to battle for the importance of the YOD nurse role; Vanessa, in particular, spoke about the sadness she felt at noticing herself becoming demotivated, and the additional emotional burden this placed on her.

Sometimes I'll sit in meetings, and I think, “Do you know I can't be bothered saying this all again? I've said it 100 times before” [slight laugh] ... other times

I'm more motivated...but... I can see it dwindling with me... it's like [tired tone] "I'm too tired now." [laughs] ... I've said it too many times and no one's listened so you know what's the point? ... you do get to that point sometimes... Horrible, horrible... when you're committed and motivated and you feel that that motivation is dwindling because you haven't got the support there it's really frustrating.

The language used by participants gives a sense of how tiring this struggle for recognition could be, with the potential for nurses to feel devalued and despondent. Challenges in gaining recognition raises concerns about the sustainability of the YOD nurse role without systemic changes.

Some participants also voiced frustration at the lack of awareness of the needs, or unique challenges, of the YOD population amongst wider healthcare and governmental systems. Laura explained, "*social care want to provide four calls to go in and... put a dinner in a microwave. They don't need that, they can do that ... and trying to explain that to social care is really frustrating.*" Vanessa recalled being met with disbelief that people could be diagnosed with dementia at a younger age when she sought employment and benefit advice for an individual. Participants also voiced frustration at the lack of financial and systemic support provided by the government for people with YOD and their families. The broader sense of the YOD population being overlooked appeared to intensify the importance of the YOD nurse role and the participants' sense of responsibility to both raise awareness of the challenges faced and to support families, given the dearth of other support available.

Despite these challenges, almost all participants emphasised their passion for YOD nursing, and their desire to continue working in this role longer-term. Participants felt valued by the people they supported, and able to make a positive

difference. Emma reflected, *“it's just nice to... feel that you can make a difference and that you can empower somebody to... give them hope... that's what... I'm here for.”*

They also spoke about enjoying the challenging nature of YOD work and the diversity of their working days, *“It's got its' challenges without doubt [smiles]... but I think we get a lot of job satisfaction... and ... every day is different. There's not one day you'll come in and you know things will be boring” (Rachel)*. These rewarding aspects of the work, and their passion to improve care for the YOD population, inspired participants to continue working in this area. However, there was a sense that despite the YOD nurses' motivation and determination to provide good care, they were being exposed to potential existential harm by working in systems which did not always understand, or support, their roles.

3. Unique Aspects of YOD Nurse Role

Although some participants' experiences likely overlapped with nurses working with older adults with dementia, there were several aspects of the role which appeared unique to YOD nursing; the emotional impact of supporting younger adults diagnosed with a neurodegenerative disease, continuing to offer this support as people with YOD approached the end of their lives, and the conflicting opinions participants held about being referred to as 'specialist' YOD nurses.

Supporting Families at a Life Stage where Dementia is not Expected

Several participants spoke about supporting family members from different generations who were unprepared for the diagnosis of YOD. Vanessa reflected on the challenge of needing to have a *“real wide knowledge and experience to...*

understand everybody's needs within the house" as participants offered support to the person with YOD, their spouse, their children, and in some cases their parents.

Supporting teenaged or younger children was challenging for some participants, like Hannah, who had limited clinical experience with this age group, and were uncertain about what their role should be. Claire spoke about her experience of witnessing younger carers: *"I do find it difficult... they're supporting their parent when... you feel that they should be out y'know doing whatever they... want to do... furthering their own.... personalities... careers, things like that."*

Children taking on caring roles appeared to be a visceral reminder for Claire of the injustice of parental diagnoses of YOD, and its' implications for the wider family. Despite the challenges of supporting younger people, several nurses felt it fell within the remit of their role, which for some may have created an internal conflict – a pressure to offer support because of a lack of available alternatives, and, simultaneously, a doubt that they were best placed to offer this.

Some participants spoke about the practical challenges of supporting people or carers who were still in full-time employment, which sometimes necessitated nurses working evening or weekend hours. There appeared to be an additional element of flexibility required from YOD nurses compared to their older adult counterparts. Given the participants' empathy for, and awareness of, the additional financial challenges faced by people with YOD and carers who needed to continue working, nurses were often willing to flex their own working hours to provide care for people with YOD and their families.

Some participants felt that younger adults struggled to accept the diagnosis of YOD because it was unexpected at their life stage, which necessitated more direct conversations than with older adults. Anna explained:

With older persons, you're sort of doing softly, softly... with this job, I feel like I've had to have some very frank conversations with people and their family members because I've had to [laughs]... I've had to learn through being quite assertive.

Encouraging acceptance and open conversations about YOD, and the challenges it presents to individuals and families, was an important aspect of the YOD nurse role. These conversations required assertiveness, confidence, and, at times, persistence which nurses who were new to working in this area may have initially found confronting.

Emotional Impact of Supporting Younger Adults' End-of-life Care

Several participants described the emotional impact of witnessing younger adults approach end of life. Laura reflected, *"it's just incredibly sad... you're seeing people that that are much younger than yourself that just haven't been able to fulfil their... full potential."* Witnessing this decline seemed to provoke a sense of injustice for participants who resonated with the life stages people with YOD were at and felt loss on their behalf.

Alongside this, some participants described feeling *"honour"* (Emma) at being able to support people with YOD and their families during an emotionally challenging time. Vanessa had a particular interest in palliative care and reflected that this element of YOD nursing was partly what drew her to the role:

I really enjoy that part... Probably what I call proper nursing really [laughs]... hands-on really getting stuck in to understanding peoples' problems, troubles... it can feel like a heavy burden, that people deteriorating ... I think being part of... their family environment as well, with that trusting relationship that... really appeals to me.

For Vanessa, end-of-life care in YOD involved problem-solving, offering compassionate and person-centered support, and building a close, trusting relationship with families. It was these aspects of care which she seemed to personally value, and which aligned with her perception of what it meant to be a nurse.

'Specialist' but Not

Participants felt conflicted about being referred to as 'specialist' nurses. Hannah explained:

When people say I'm... the specialist young onset dementia nurse, I always tell them I'm not the specialist because I'm not... I haven't done specific training. I'm a specialist because I'm the only one doing it... but otherwise I'm not a specialist, I don't feel like a specialist.

For her, the term "*specialist YOD nurse*" appeared an affront. It inherently suggested that nurses had completed specialist training, or held clinical expertise in YOD, which did not always reflect participants' lived experiences of the role. Even for those who had received additional training, their specialism had not been recognised financially. Emma explained:

It [completing a Masters in dementia] didn't change my role as far as pay... some Masters you get paid... You get band 7... if you're an advanced nurse

practitioner. If you did a specialist course in dementia, you don't get...

anything so that that kind of smarts a little bit... why is one more valuable than the other?

This financial injustice when compared to other nursing specialisms could be perceived as another reflection of the wider lack of recognition of the significance of the YOD nursing role.

In addition to their roles, several participants felt their services would be improved by recruiting YOD Consultant Psychiatrists, who could be an additional source of support and expertise for YOD nurses and could help to develop service provision for the YOD population.

Rachel and Emma received YOD training at the beginning of their employment as YOD nurses; however, this was not a common experience. Most participants had not received YOD training and this created a concern for those who did not feel they knew enough. Laura reflected:

It's quite scary... we got somebody with CADASIL and I was like, "...what the hell is CADASIL?"... Oh my gosh, so there I was y'know, on the Internet... scrolling away, "what is CADASIL?" before I went out and met this person.

Several participants expressed fear that they would be unable to answer questions posed by people with YOD and their families. Hannah reflected, *"I worry... if I'm going out to someone and they ask me questions and I don't know the answer, it's like, 'well, aren't you the... nurse that should know?'"* Participants felt that being referred to as 'specialist' nurses meant people with YOD and their families had high expectations, which nurses felt unable to meet. In some ways this seemed unjust, given that most participants had not received specialist training.

The lack of specialist training appeared to increase participant's drive to develop their own clinical knowledge. Vanessa recalled, *"it's just continually... continually learning all the time... most of it is coming back and Googling what could this be, speaking to the consultants, you know, 'this is really different, you know, why could it be different?'"*

It is conceivable this continued learning and requirement from nurses themselves to seek learning opportunities could be quite effortful, and that never fully achieving 'mastery' of their clinical area could be demoralising; however, most appeared to enjoy the ongoing learning nature of the YOD nurse role, and felt they benefitted from continually developing their knowledge, *"it's a challenge I enjoy"* (Anna).

Discussion

The study aimed to explore the experiences of a group of nurses working with people with YOD in the UK. Throughout interviews, it was evident that the YOD nurse role was one that all participants had enjoyed and found rewarding; however, it was not without its challenges. Analysis of the interviews with participants identified three main group experiential themes; tensions between participants' personal and professional lives, systemic challenges faced by the participants, and unique aspects of their roles as YOD nurses. Within each of these overarching themes there were several sub-themes.

The first theme highlighted participants' experiences of tensions between their personal and professional lives, and the ways in which these added to the emotional intensity of the role. Some participants with familial experiences of YOD reflected on being drawn to work in this area because of motivations to improve care following

their own family members' experiences. These motivations could also be conceptualised within the 'wounded healer' theory, which suggests people are drawn to areas of work, such as nursing, because of a compassionate desire to relieve other's distress after experiencing difficult or traumatic events in their own lives (Conti-O'Hare, 2002).

Several participants spoke about the emotional intensity of the role and the impact this had on them personally and professionally. Participants may have felt the emotional impact of this role more intensely as a result of developing close relationships with people and their families, and supporting people who they could resonate with personally, who were of similar ages, and at similar life stages to them. The emotional impact of working with people with YOD whose lives 'mirrored' the professionals' own, was a theme which emerged in previous research (Ducharme et al., 2014; Ottoboni et al., 2021).

The emotional intensity of the role, coupled with the second theme of systemic challenges (e.g., professional loneliness within teams) faced by these participants, resulted in an increased sense of individual responsibility for the people the YOD nurses supported. Irregular, or non-existent, professional support and supervision brought into question the sustainability of the YOD nurse role, despite participants' passion for it, without systemic changes to the support offered to these nurses.

It is well-documented that the lack of resources and support for people with YOD and their families is a source of frustration for healthcare professionals (Ducharme et al., 2014; Kilty, 2019; Ottoboni et al., 2021) and previous research has highlighted the powerlessness experienced by professionals in relation to this

(Ducharme et al., 2014). Within the current study, too, the lack of appropriate services and resources for people with YOD generated a feeling of powerlessness for the participants, however there appeared to be an additional layer of complexity added to this as the participants reflected that it was them, as YOD nurses, who had to explain the lack of resources to families referred to them for 'specialist' support. Participants reflected that this often led them to feel inadequate and as though they were unable to do their jobs to a standard they would like. This is suggestive of moral injury (Litz et al., 2009), with nurses striving to do their best for individuals and families but feeling unable to do so as a result of systemic restrictions. This experience of moral distress for healthcare professionals trying to navigate services which were not appropriate for people with YOD was also identified by Kilty and colleagues (2019).

Although nurses reflected on the rewards of the role, a sub-theme of the systemic challenges they faced emerged when participants spoke about difficulties in gaining recognition for their role from senior management and the lack of awareness of YOD amongst other healthcare professionals and services. Although the lack of recognition felt by YOD nurses was not raised elsewhere in the literature, previous research highlighted the need for further training and awareness-raising to be offered to healthcare professionals and the general public to enable them to better understand and support people with YOD (Ducharme et al., 2014; Ottoboni et al., 2021).

The final theme identified in the current study emphasised some of the unique aspects of the YOD nursing role, such as supporting whole families who are experiencing an 'off-time' diagnosis of dementia, the simultaneous emotional challenge and privilege of supporting younger adults at the end of their lives, and the

discomfort at being referred to as 'specialist' without necessarily having specialist training, or financial reimbursement for this title. There was a sense that for some nurses, despite feeling valued by the individuals and families they supported, this appreciation was not always reflected by senior leadership and management within the health service.

Implications for Policy and Practice

This study highlights the important and unique role occupied by YOD nurses. Although participants working in these roles were passionate about their work, some reflected on feelings of sadness, guilt, and injustice about supporting people who were similar ages to them with life-limiting diagnoses. It is imperative that the personal resonance of this work is recognised, and supported, by clinical and system managers who are responsible for the care and support of these nurses. Many participants felt a sense of professional isolation, facing barriers in accessing regular, supportive supervision or peer-support. Services could support the emotional wellbeing of these nurses by ensuring access to regular professional supervision. This seems particularly important given the unique issues faced by YOD nurses, such as concerns about end-of-life, moral issues about assisted dying, developing close relationships, and offering support to individuals and families that can resonate so personally. Encouraging and making space for YOD nurses to also attend peer-supervision groups may help to facilitate a sense of belonging and connectedness with other people working in this area. These provisions may help to improve staff wellbeing, staff retention and continued sustainability of this demanding role.

This study highlights the importance of the YOD nurse role and how valued this is by nurses themselves. With increasing rates of YOD diagnoses (Carter et al.,

2018), it is conceivable that there will be an increased demand for nurses to work in these roles. Developing further training around YOD may help to lessen existing YOD nurses' feelings of inadequacy and self-doubt about their knowledge, as well as promote further interest in this role and raise awareness amongst other professionals and services about the unique needs of this population. This in turn, may lead to YOD nurses feeling more supported by other services, and could lead to the investment and creation of additional resources for the YOD population.

Strengths and Limitations

To the best of our knowledge, this was the first qualitative study to explore the experiences of YOD nurses working in the UK. Although the results are not generalisable to all nurses working in this clinical area, this study provides a rich and unique insight into the experiences of some nurses working with the YOD population and the challenges they face.

A limitation was that all participants were female, future research may endeavour to recruit a broader gender sample, where possible. There was some heterogeneity within the sample, where participants were recruited from services which operated in different ways, and from different areas of the UK. Findings may be influenced by a selection bias, as YOD nurses who had particular perspectives they were keen to discuss may have been more likely to participate.

Recommendations for Future Research

Future research could explore in more detail areas of interest within the study, such as the personal resonance of the YOD nurse role, the potential for moral injury as part of this work, or YOD nurses' experiences of professional or peer support. It would also be worthwhile to consider the experiences of other professionals working

with the YOD population, and to explore any similarities or differences to the experiences of YOD nurses.

Conclusion

This study explored the lived experiences of a sample of mental health nurses working with people with YOD in the UK. Findings indicate that these nurses experienced tensions between their personal and professional lives, while also facing systemic challenges within their role, including limited availability of professional support and a lack of recognition from senior management of the value of their work. Nurses also reflected on the unique aspects of working with younger adults who are diagnosed with dementia. This study emphasises that despite these nurses' passion for their roles, they are working in clinically complex situations without adequate levels of clinical or professional support. It is imperative that services take action to support the emotional wellbeing and sustainability of nurses working in these challenging roles.

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Appendices

Appendix A – Ethical approval following amendments on Bangor University Ethics Portal

Application number:	2022-17212-A14923
Project Title:	Exploring the experiences of nurses working with people with Young Onset Dementia in Wales
Amendment requested by:	Browne, Stephanie
Principal Investigator:	Browne, Stephanie
Study Start Date:	03 Oct 2022
Study End Date:	29 Sep 2023
Other Researchers:	Piggin, Lucy - Agreed  I have made some changes to the recruitment strategy as part of this project. I will no longer be recruiting within Betsi Cadwaladr University Health Board and will no longer be limiting recruitment to within Wales. Instead, I will be recruiting using professional bodies and networks e.g., Royal College of Nursing, Association of Clinical Psychologists UK, and third sector organisations/charities e.g., Dementia UK, Young Dementia Network, within the UK.
Nature of Amendment:	As such, I have made changes to the following attached documents – participant information sheet, consent form, research proposal, debrief form and my recruitment materials. I have also included a brief word document outlining the purpose of the research, what it would involve, and my role, which can be shared with professional networks and third sector organisations/charities, alongside recruitment posters. The research aims and procedures remains the same.
Department	[Pre-Aug 2021] School of Psychology
LAST MODIFIED: 12 Oct 2022 03:29p.m. by stb20fyg	

Review

Happy to approve

Approval Status: Approve

Appendix B – Participant Information Sheet



RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



Exploring the experiences of nurses working with people with Young Onset Dementia in the UK

Would you like to take part in our research study?

We are looking for nurses who have current **OR** previous experience working with people with Young Onset Dementia in the UK.

What is our study about?

We want to learn more about the experiences of nurses who are currently working, or who have previously worked, with people with Young Onset Dementia (YOD) – that is, people diagnosed with dementia before the age of 65 years.

Understanding more about nurses' experiences in these roles is important to help services better support their work and promote their wellbeing.

Who are we looking to speak to?

- Adults aged ≥ 18 years.
- Currently or previously working/worked as a qualified nurse in the UK.
- Worked either in a specific YOD nurse role for a minimum of 6 months (currently or at another time within the past 10 years) **OR**
- Worked in a generic older adult nurse role, but with specific involvement with people with YOD for a minimum of 6 months (currently or at another time within the past 10 years).

What would be involved?

- A 50-90 minute interview with Stephanie Browne (Trainee Clinical Psychologist) about your experiences of this type of work and what impact it has had on you.
- The interviews will be audio or video recorded and transcribed by the researcher.
- You will also be asked to provide some basic information about yourself and your nursing role.

Participant Information Sheet

You are invited to take part in a research study. This study is part of a doctoral qualification. The aim of this information sheet is to help you to understand why the research is being undertaken, and what it will involve, before you decide whether you would like to take part. Please take time to read the following information carefully. You are welcome to share this information with anyone else who might help you to make a decision. However, it is up to you to decide whether or not you would like to take part. You are encouraged to contact the research team if there is anything that is not clear, or if you would like further information.

What is the purpose of this study?

This study aims to explore the experiences of nurses who are currently working, or who have previously worked, with people who have Young Onset Dementia (YOD) in UK settings. People with YOD are those diagnosed with dementia before the age of 65 years.

The experience of having dementia at a younger age has several potentially unique implications for the individual, their family, and surrounding support networks, which adds complexity to the broader care and support needs of this population. Previous research has explored the experiences of nurses and other healthcare professionals' working with older adults living with dementia. However, there is currently a lack of research exploring the personal and professional experiences of nurses working with younger adults with dementia.

We would like to know what it is like to work with this population, whether you are currently working with people who have YOD or have done so in the past. If you have now left this role, we would be interested to hear if you had any specific personal or professional reasons for doing so.

Understanding more about nurses' experiences of working with people who have YOD in the UK may help services develop strategies to support their work and promote their wellbeing. This in turn, may enhance client care and help provide a more supportive service for people living with YOD in the UK.

Why have you been invited to take part?

You have been invited to take part because you are a qualified nurse and currently work with, or have previously worked with, people with YOD in the UK. Therefore, you have the experience and knowledge we are interested in learning more about.

What would taking part involve?

If you agree to take part, you will be asked to complete an interview with the principal researcher Stephanie Browne (Trainee Clinical Psychologist). In this interview, you will be asked about your experiences of working with people with YOD, including the impact that this work has had on you personally and professionally. You will also be asked to provide some basic information about yourself (e.g., your age) and your professional role (e.g., how long you have been a nurse and/or working with people with YOD). You can request to see the questions that will be asked before the interview.

The interview will take place at a time and date which is mutually convenient. This may be within your working hours, if requested. You will be offered a choice of being interviewed over the telephone, or via online video conferencing, depending on your preference.

All interviews will be audio or video recorded and transcribed by the researcher.

Do you have to take part?

No, your participation is entirely voluntary. If you decide to take part, you should keep a copy of this information sheet and you will be asked to sign the attached consent form. In interviews, you can omit any question that you do not wish to answer. You can also end the interview at any time and do not have to give a reason or explanation.

What are the possible benefits and risks of taking part?

In contributing to our shared knowledge of what it is like to work with and support people with YOD, there is potential benefit for young people living with dementia, as well as other professionals working within this field.

Participation may also be of personal benefit to you by providing you with an opportunity to reflect on your experiences working in this area. However, it is also possible that there will be no benefit to you personally.

All participants will be compensated for their time with a £20 online retail voucher.

It is not anticipated that taking part in this study will cause any risks or discomfort to you. However, it is possible that discussing your experiences may cause some distress. If appropriate, you can be signposted to additional support services.

How will confidentiality be maintained?

All the information you share as part of the study will be kept confidential. When the interview is transcribed, you will be identified by a number, which will be known only to the research team. You will not be identified by name in any report, thesis, or publication that arises from this study. We will anonymise transcripts to remove any information that might make it possible to identify you (e.g., the names of people and places).

To help convey your experiences accurately, we would like to use anonymous quotes from your interview responses. All efforts will be made to ensure that no information will be contained in quotes that would enable anyone else to identify you.

Any personal information collected (e.g., signed consent forms and demographic information) will be stored securely at Bangor University, where it will only be accessible to the research team. This information will be stored for 10 years and then destroyed in line with Bangor University guidelines.

What are the limits of confidentiality?

If any participant discloses information during an interview that indicates a risk of significant harm, either to the participant or another person, this information will need to be shared to ensure safety. We will always discuss this with you before doing so.

How do you withdraw?

You may withdraw from this study by contacting the researcher prior to the interview using the details below, with your name and contact details. You can also choose to stop the interview and withdraw at any time. Please note that once the interview data has been collected, it will not be possible to withdraw your data. However, you are welcome to contact the researcher if you wish to discuss any concerns.

What will happen to the results of the study?

The results of the study will be published as part of a doctoral thesis and may be published in a journal article. The results will also be disseminated through oral presentations at conferences and seminars. The results may also be used for teaching purposes or to inform future research. Only anonymised data will be shared.

If you would like to receive a brief written summary of the main findings of the study, please indicate this on the attached consent form.

Who has ethically reviewed the study?

The study has been reviewed and approved by the School of Psychology Research Ethics Committee at Bangor University.

Who can you contact if you have any concerns about the study?

If you have concerns about the study, please contact a member of the research team in the first instance (contact details below).

If you still have concerns or wish to raise a complaint about this study or the conduct of its researchers, please contact Huw Roberts, College Manager, College of Human Sciences, Bangor University on +441248383136 or huw.roberts@bangor.ac.uk

Who can you contact for further information?

If you have any further questions about the study, please contact:

Principal Researcher: Stephanie Browne, Trainee Clinical Psychologist, North Wales Clinical Psychology Programme, Bangor University, LL57 2DG. stb20fyg@bangor.ac.uk

Academic Supervisor: Dr Lucy Piggin, Clinical psychologist and Research Tutor, North Wales Clinical Psychology Programme, Bangor University, LL57 2DG. L.piggin@bangor.ac.uk

Clinical Supervisor: Dr Fiona Sanders, Principal Clinical Psychologist, Glan Traeth Community Team, Royal Alexandra Hospital, Rhyl, LL18 3AS. Fiona.sanders@wales.nhs.uk

Appendix C – Participant Consent Form



RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



Consent Form

Exploring the experiences of nurses working with people with Young Onset Dementia in the UK

Please enter your initials in each box as relevant

☐

I confirm that I have read the information sheet dated 05.10.22 (version 3.0) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

☐

I understand that my participation is voluntary and that I am free to withdraw without giving any reason.

☐

I understand that participating in this research will involve a one-to-one interview and providing some clinical and demographic information.

☐

I agree to the interview being audio or video recorded.

☐

I understand that my data will be anonymised (e.g. I will be assigned a code and a pseudonym).

☐

I understand that direct quotes (anonymised) will be used and may feature in the write-up and any potential publications that may follow from this research.

☐

I understand that data collected about me as part of this project may be looked at by the research team. I give permission for these individuals to look at my data.

☐

I understand that I am free to ask questions or to discuss any concerns with the researcher at any time.

☐

I understand that the data I provide me may be used for research dissemination, teaching and to support other research in the future.

☐

I agree to take part in the above study.

☐

I would like to receive brief written feedback about the findings of this study.

If you would like to receive brief written feedback about the findings of the study, please provide contact details below:

.....

.....

.....

Name of participant

Date

Signature

Name of Researcher

Date

Signature

Principal Researcher: Stephanie Browne, Trainee Clinical Psychologist, North Wales Clinical Psychology Programme, Bangor University, LL57 2DG. Stb20fyg@bangor.ac.uk

Academic Supervisor: Dr Lucy Piggin, Clinical Psychologist and Research Tutor, North Wales Clinical Psychology Programme, Bangor University, LL57 2DG. L.piggin@bangor.ac.uk

Clinical Supervisor: Dr Fiona Sanders, Principal Clinical Psychologist, Glan Traeth Community Team, Royal Alexandra Hospital, Rhyl, LL18 3AS. Fiona.sanders@wales.nhs.uk

Appendix D – Interview Schedule

Proposed Interview Schedule

Check consent form, confidentiality, understanding about the interview process, right to withdraw, decline questions, recording, breaks, support if the interview raises issues that cause distress, any questions?

Demographic Questions:

Gender:

Years working as a nurse:

Years working with people with YOD:

Briefly what your role with people with YOD involves/ed e.g., assessment, care co-ordination, post-diagnostic support etc.:

What is your current role?

- How long have you worked with people with YOD? (if not already asked)
- How did you come to work with people with YOD?
- What was/is it like working with young people with dementia?
- What are some of the challenges or rewards of working with young people with dementia?
- What are some of the unique features of working with this client group? (e.g., any unique differences/challenges in comparison to working with older adults with dementia, any systemic challenges in signposting people to other support services, residential or end-of-life support)
- I wondered whether working with young people with dementia has had an impact on your personal life? If so, how? (e.g., any emotional or personal impact of working with this group, whether any personal impact on them changed over time)
- Do you feel/have you felt sufficiently prepared for, and trained in working with this client group?
- To what extent do you feel/have you felt supported to work with this client group (e.g., by peers, colleagues, managers etc.)?
- Would you like to continue working with this client group longer-term?
- For people who are no longer working with this client group, what influenced your decision to move on from that work?
- Is there anything else you would like to mention, or anything that feels important that has not been asked about?

- How are you feeling at the end of interview? E.g., whether they are feeling any distress or need signposting for additional support.

Appendix E – Debrief Sheet



RHAGLEN SEICOLEG CLINIGOL GOGLEDD CYMRU
NORTH WALES CLINICAL PSYCHOLOGY PROGRAMME



Exploring the experiences of nurses working with people with Young Onset Dementia in the UK

Debrief Information

Thank you for participating in our research. We really appreciate you sharing and discussing your experiences with us.

The aim of our research is to explore and learn more about the experiences of nurses who are working, or have previously worked, with people with Young Onset Dementia in the UK. We hope that by learning more about these experiences, we may be able to help local services develop strategies to support nurses working in these roles and to promote their wellbeing. We hope that this, in turn, may enhance the service and care provided to people living with Young Onset Dementia.

We appreciate you discussing your experiences with us, and hope that this was not a distressing experience for you. If, however, you have felt distressed discussing these experiences and wish to seek further support surrounding this, please be aware of local services you can contact for support with your wellbeing, such as:

- If you are currently employed by the NHS, you can ask for support from your local Occupational Health or Staff Wellbeing Department. The contact details for these departments can typically be found on your local Health Board or Trust's Intranet.
- All NHS staff can access free wellbeing support by text 24/7. Text FRONTLINE to 85258 to talk by text with a trained volunteer.
- The Samaritans offer telephone wellbeing support for NHS staff in England on 0800 069 6222.
- The Samaritans offer telephone wellbeing support for NHS staff in Wales on 0800 484 0555, daily from 7am–11pm. To speak with a listening volunteer in Welsh call 0808 164 2777, every evening 7pm-11pm.
- For support across the UK from the Samaritans, call 116 123.
- You can also seek support from your GP or local support service.

If you have any further questions or concerns about the study, please contact: Stephanie Browne, Trainee Clinical Psychologist, North Wales Clinical Psychology Programme, Bangor University, LL57 2DG. stb20fyg@bangor.ac.uk

If you have additional concerns or wish to raise a complaint about this study or the conduct of its' researchers, please contact Huw Roberts, College Manager, College of Human Sciences, Bangor University on +441248383136 or huw.roberts@bangor.ac.uk

Thank you for your time and participation

Appendix F – Example of exploratory notes and experiential statements arising from these

<p>Challenge of trying to support families across different stages of the lifespan, when there is an 'off time' diagnosis</p> <p>and breadth of knowledge, awareness and effort this requires from YOD nurse</p> <p>Rewarding to see people benefit from support/resources you've implemented</p>	<p>Participant: Erm I suppose everyone's got different needs, haven't they? You know, you're trying to erm swap, erm I suppose if you're looking after someone whose, you know you were going out to see people who were in their 80s, and have got dementia, it might be their partner or their sons, daughters, but it's trying to manage all those different ages. You know the the children, the partners, elderly parents, there's <i>a lot</i> I think isn't there a lot of family dynamics as well and people living in houses where, I've got a gentleman whose grandchildren live with them, they're their legal guardians for them as well so they're they're really small children within that home, so it's managing all that safeguarding everybody's need so I think you need to have a a real <i>wide</i> knowledge and experience to to understand <i>everybody's</i> needs within the house. So yeah, that that can be quite hard at times.</p> <p>Interviewer: Yeah, I can imagine. Amm, okay and I wondered what are some of the rewards of working with young people with dementia?</p> <p>Participant: Erm I mean, I mean it, it is rewarding. Obviously, you're not seeing people getting better, but you can see situations improving once you've put support services, when they want, people are understanding what's going on eh that can be really rewarding. I always find <i>most</i> of the people that I see are really lovely people (smiles).</p>	<p>Individual needs – all different</p> <p>Comparison with older adults with dementia</p> <p>Difficulty of trying to manage whole family dynamics and difficulties across age ranges and generations</p> <p>Maintaining safety for everyone where there are different generations living within one household This necessitates a wide range of knowledge on nurses' behalf to understand the unique challenges/needs of everyone within the household – can be hard. ?juggling lots ?looking after whole family not just person with YOD</p> <p>Recognition that although not seeing people improve in their condition, can see situations improve with support and understanding Majority of people are lovely to work with ?means some are not</p>
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Appendix G – Analysis of experiential statements and personal experiential themes drawn from these



Chapter Three

Contribution to Theory and Clinical Practice

Contribution to Theory and Clinical Practice

This thesis sought to understand more about different aspects of the experiences of healthcare professionals working with people with dementia across the lifespan. The systematic review considered the attitudes towards, and experiences of, healthcare professionals towards assisted dying in people with dementia. The empirical paper explored the experiences of a sample of mental health nurses working with people with young-onset dementia in the UK. This final paper will consider the findings of both papers in terms of their contributions to theory and future research, and their implications for clinical practice, and will conclude with a reflective commentary on the research process.

Implications for Future Research and Theory Development

Systematic Review

Theory Development

One of the arguments put forth in support of assisted dying is the value placed on individual autonomy, and the right to die compared with the right to live (Jahkar et al., 2021). The degenerative nature of dementia, which leads to diminished mental capacity for decision-making, is considered by some to be associated with a loss of autonomy (Rahjkumar et al., 2021). It has been argued elsewhere that autonomy-based arguments for assisted death in dementia are particularly prevalent in Western societies (Cipriani & Di Fiorino, 2019). With this understanding, as all the studies included in the review were conducted in arguably Western societies, the societal value placed on autonomy may have influenced people with dementia's

decision to consider an assisted death and may also have influenced the attitudes of some Healthcare Professionals (HCPs).

Advance directives, including Advanced Euthanasia Directives (AEDs) can preserve a person's autonomy by outlining in advance their wishes when they no longer have mental capacity to make health-related decisions, which is considered a form of prospective autonomy (D'cruz., 2021). However, as the systematic review indicated, these AEDs are not always complied with, particularly when people with advanced dementia are no longer able to engage in reciprocal communication with HCPs. While there is no obligation to provide an assisted death based on an AED (de Boer et al., 2011), it invokes a dilemma for HCPs who endeavour to balance patient autonomy with what they personally feel is morally and ethically permissible. It could be considered that by not following these directives, HCPs are inadvertently lessening the autonomy afforded to people with dementia. However, the situation is not this clear-cut, and our systematic review adds to this debate by acknowledging that HCPs' attitudes towards, and experiences of, assisted dying, and the use of AEDs in this population, are nuanced and influenced by several clinical, professional, and personal factors.

Future Research

Studies included in this review used several different forms of questionnaires and clinical vignettes, to understand more about HCPs' attitudes and experiences, leading to differing forms of data collected, which may also be different in terms of quality, which can make it challenging to make cross-professional and cross-cultural comparisons. Developing a standardised questionnaire could help to overcome some of these challenges and facilitate a more homogenous review of HCPs' attitudes towards assisted dying in people with dementia.

Previous research has considered the attitudes and views of HCPs, particularly GPs, in the UK towards assisted dying more broadly (Hussain & White, 2009; McCormack et al., 2011; Pasterfield et al., 2006) and largely found that UK HCPs were not in favour of this approach. However, given the possibility of legislation to permit assisted dying in Jersey later this year (Gajjar & Hobbs, 2022), it would be timely to explore the contemporary views of HCPs on assisted dying, and particularly as legislation grows elsewhere, on assisted dying in dementia within the UK. In connection with the empirical paper, it may also be worthwhile to consider further qualitative research on how nurses, and other HCPs, manage conversations around assisted dying when these are raised by people with dementia, or Young Onset Dementia (YOD), particularly in jurisdictions where this is not permissible by law – including the UK.

Empirical Study

This study considered the lived experiences of mental health nurses working with people with YOD and their families.

Through the experiences of the YOD nurses who took part in this study, their exposure to moral injurious situations became clear. Moral injury refers to the cognitive and emotional response an individual feels when they either enact, or fail to prevent, something that goes against their personal morals, values, or ethics (Litz et al., 2009). Moral injury can result in people experiencing a range of difficult and uncomfortable feelings, including guilt, shame, loss of trust and frustration (Williamson et al., 2021) all of which were cited by the YOD nurses within this study. Nurses spoke about the emotional distress they experienced when they were unable to meet the needs of the people and families they supported due to systemic challenges, such as a lack of appropriate services or resources and a perceived lack

of interest and recognition from more senior management of the value of their work. This distress appeared to be intensified by the YOD nurses' reflections that they had limited capacity to influence or change these factors themselves.

The study explored the overlap between some nurses' personal and professional lives, when discussing their motivations for working with people with YOD in particular. Two nurses spoke of their family member's diagnoses of YOD and the lack of appropriate support and information they felt they received following their diagnosis. Both nurses spoke about how their family's experiences had motivated them to improve care for other people with YOD and their families. The theory of nurses as 'wounded healers' (Conti-O'Hare, 1998; 2002) can support understanding of these participants motivations for embarking on careers within YOD nursing. Facets of this theory suggest that people enter caring professions in part, because their own experience of difficulty or distress (families feeling let down by lack of YOD services or support) facilitates a connection with the people they support, and helps them to better understand and support the needs of others in similar situations (Conti-O'Hare, 2002).

It has been recognised previously that emotionally supportive relationships are often dependent on the nature and quality of the interpersonal relationship between nurses and the people they support (Skilbeck & Payne, 2003). Throughout the study, the importance of the close relationship between YOD nurses and the people they supported was clear. The significance of therapeutic relationships and their benefits have been studied across different areas of mental health nursing (Dziopa & Ahern, 2009; Hewitt & Coffey, 2005) but this study highlights the importance of the therapeutic relationship in YOD nursing, in particular. Here, the therapeutic relationship between people with YOD and YOD nurses is integral to the

support provided by YOD nurses, particularly given the length of their involvement, their support for the whole family, and the care provided as the dementia progresses. Nurses in this study spoke about how the closeness of their relationships with people facilitated more person-centred support, but also meant that people with YOD and their families could be open and trusting of the YOD nurse.

Future Research

Future research could expand on areas of interest within the study, such as the tensions between the YOD nurses' personal and professional lives, the emotional impact of systemic challenges they face, the morally injurious nature of their work, or their experiences of professional and peer support.

In future, it may also be of interest to explore the experiences of other professionals working with the YOD population, and to consider any similarities or differences between professional groups' experiences of working with the YOD population. In particular, there was expressed interest in this study from Occupational Therapists working with people with YOD across different areas of the UK.

A limitation of this study was that all participants were female. The gender ratio of nurses working in this area is unclear, however it would be worthwhile for future research to recruit a broader gender sample, and to consider any impact gender may have on the experiences of YOD nursing.

Implications for Clinical Practice

Systematic Review

Some of the studies included in this review reflected on the emotional burden and responsibility felt by HCPs who either receive requests from people with dementia, or who are involved in the decision-making process, for individuals with dementia who seek an assisted death. Varying levels of support appeared to be available to these professionals to help them manage the personal and emotional impact of their work. Implementing more regular psychological and spiritual support for these HCPs, as well as making them more aware of existing avenues of support, may help them to experience less stress, moral distress, and frustration around requests for assisted dying from people with dementia.

Some HCPs (Bravo et al., 2022b; Schuurmans et al., 2020) mentioned areas of dementia care and assisted dying that they would like to develop their skills in. These included assisted dying, and legislation around this in dementia, AEDs, communication skills, advance care planning and the dementia trajectory. Providing training in these areas, as well as any others highlighted as important by HCPs working in dementia and assisted dying settings, could help to increase HCPs' confidence in navigating some of the challenges they face around assisted dying requests, and practices in people with dementia.

Raising awareness of the use, and limitations, of AEDs more generally within jurisdictions where these are used, as well as promoting good quality of life amongst people living with dementia, may help to reduce some of the stigma associated with this diagnosis on a wider societal level, and may help to improve the care received

by people living with dementia and their families, as well as the care provided by HCPs.

In the UK, the campaign Dignity in Dying, continues to advocate for access to assisted dying for individuals who have six months or less to live, to allow them to control the manner and timing of their death (Dignity in Dying, n.d.) The Royal College of Physicians and the British Medical Association (BMA) both hold a position of neutrality, meaning they would neither support nor oppose proposed changes to the law on assisted dying in the UK (BMA, n.d.). However, neither professional body appeared to have current accessible guidance on how physicians should approach conversations, or requests, for assisted dying generally, or in people with dementia. Guidance developed by the Royal College of Nursing (RCN; 2016) suggests that if nurses or healthcare support workers are approached by a person who expresses a wish for an assisted death, or for more information about this, they can acknowledge this request but should make it clear that they cannot act on this or provide further information. They are instructed that if they feel comfortable to, they may explore this conversation further but with the intent to uncover the meaning that has led to this wish (RCN, 2016). There is, however, no specific guidance on broaching these conversations in people with dementia and their families, who, as is evident from the systematic review and from the experiences of some of the YOD nurses interviewed in the empirical paper, may wish to pursue this. Providing clear guidance on how to discuss assisted dying in people with dementia for HCPs who support people living with dementia, and their families, could allow HCPs to feel more confident in having these conversations, and less distressed if these topics are raised.

While HCPs in jurisdictions where assisted dying is illegal may be fearful about engaging in conversations around assisted dying with people, some research

indicates that allowing space for people to discuss their wishes for assisted deaths, and providing them with an opportunity to express their fears and concerns about their diagnoses, was therapeutic, without the person necessarily pursuing an assisted death (Norwood, 2007). Creating this space could also be considered a way of giving the individual some autonomy back, and allowing them to voice their desires, even if these are not ultimately acted upon (Norwood, 2007). This may be particularly relevant, in jurisdictions, such as the UK, where assisted dying in dementia is not legal, but nonetheless HCPs could be encouraged to allow people to have conversations about this topic.

Empirical Paper

Several participants reflected on the similarities they observed between themselves and the people they supported, who were often a similar age and at a similar life stage to them. This often led them to experience feelings of guilt, sadness, and injustice. Participants reflected that they often coped with the emotional aspect of their role in isolation and cited several barriers to accessing regular clinical supervision or peer support.

The term 'clinical supervision' can cause confusion and is sometimes associated with forms of managerial appraisal. Here, clinical supervision refers to the model developed by Proctor (1986) based on normative, formative, and restorative functions of supervision. Within this model, clinical supervision encourages nurses to reflect on their practice, ensuring they are acting ethically and professionally (normative), while developing their skills and knowledge (formative), and providing a space to process the emotional impact of their work (restorative) (Wallbank & Hatton, 2011).

It is imperative that services and senior management recognise the value that clinical supervision brings to both staff development and the patient care they provide (Bifarin & Stonehouse, 2017) and are active in developing routine clinical and peer supervision for this population of nurses. It is important in establishing supervision that it is a consistent and long-term practice, as it has been acknowledged that the provision of short-term or ad-hoc clinical supervision is not beneficial to nurses (Edwards et al., 2005).

Nurses working with people with YOD should be supported by management to attend regular clinical supervision, alongside opportunities for informal peer supervision. Clinical supervision could be facilitated by Clinical Psychologists, or other therapeutic staff working within teams, and could provide in-house support for those YOD nurses in particular, who are the only person within their team in that role.

Peer-supervision with other nurses working with people with YOD should also be facilitated and could encourage a sense of community and connectedness for nurses, many of whom reported feelings of professional isolation or loneliness. As large geographical distances were a barrier to accessing regular peer support, it is possible some peer-supervision could be facilitated online and thus reduce the need for YOD nurses to travel long distances to access support.

If acted upon by services, these initiatives may improve YOD nurses' emotional wellbeing, staff retention, and continued sustainability of the role, which in turn is likely to benefit the people and families they support.

It is possible that nurses supporting people with neurological illnesses, or living with brain injuries, could be an additional source of peer support for YOD

nurses, and developing links with nurses working in these areas should be encouraged.

Almost all participants spoke about the wider lack of specific resources available to people with YOD and their families, and the need for more age-appropriate resources for this population, which has been well-recognised elsewhere (Beattie et al., 2002; Cations et al., 2017; Stamou et al., 2021). However, this study further highlighted the emotional impact this has on YOD nurses, some of whom reported feelings of distress, guilt, and inadequacy when they were unable to support people to access appropriate services for YOD. As the number of people diagnosed with YOD is expected to rise (Carter et al., 2018) it is important that specific, age-appropriate resources and services are designed to meet the needs of people with YOD and their families. The development of such services would likely also lessen the emotional burden felt by YOD nurses who often try to fill this gap in service provision themselves with limited resources.

Training developed on YOD by national governments or professional bodies could help to raise awareness of YOD amongst other health and social care professionals, a need which has been recognised elsewhere (Ottoboni et al., 2021) and could help YOD nurses to feel better supported and understood in their role. Further awareness of YOD and the challenges faced by nurses working in this area, as well as people with YOD and their families, could also lead to investment in further resources and staffing for this population.

Providing access to further training around YOD to nurses may also help to increase their confidence in the role and could encourage further interest in the role of YOD nurses, from other nursing staff.

Personal Reflections

I have found the research process for this project simultaneously challenging and exciting. Having limited prior research experience, I was at times doubtful about my ability to complete the research successfully, particularly the systematic review, which often felt overwhelming. I doubted whether I was doing things 'right' or whether I was drawing reasonable conclusions from the data. I was aware of the importance of doing justice to the experiences of the YOD nurses I interviewed, and to the previous researchers whose work I was reviewing, which both motivated and concerned me. However, the process of completing the project, and the support I received from my supervisors, allowed me to develop some confidence in my research abilities.

Reading in more detail about HCP' views and experiences of assisted dying in dementia prompted regular reflection on what my own perspective on this topic was. In particular, it prompted me to reflect on my experience prior to clinical training, working as a support worker on an inpatient ward for people with advanced dementia, some of whom reached the end of their lives whilst on the ward. I recalled a particular patient who appeared to suffer greatly prior to their death, and remembered the conversations that had occurred amongst staff, who debated the benefits and challenges of the potential for assisted deaths in such cases. At the time, I recall feeling unsure what I believed to be most appropriate, and debated how I would feel it if were myself, or a member of my family, in the patient's position. Completing this research has not made me any more certain of my personal beliefs on such a complex topic. However, it has made me much more aware of the nuances of assisted dying within dementia, the grey areas which exist, and the

challenges they present for healthcare professionals, particularly those who are in a position of performing any potential assisted deaths.

Interpretative Phenomenological Analysis (IPA) recognises through the 'double hermeneutic' the researcher's role in making sense of participants making sense of their lived experiences (Smith, 2004). As such, it is important to reflect and consider how I may have been influenced during the research process.

Throughout the interview process for the empirical paper, I was struck by the passion and enthusiasm of each of the participants for their chosen career paths, despite the challenges they faced. I was also mindful of how busy participants were in their clinical roles, and how generous they had been in offering their time to take part in the research. I was keen to share as much of their experiences using their own words as possible, and sometimes struggled with the balance of sharing their direct quotes and my interpretations, all within a limited word count.

I noticed during interviews that when I asked broad questions such as, "What is it like to work with people with YOD?" participants often initially responded by commenting on service procedures, or the challenges people with YOD and their families faced generally. Participants often required further prompting to consider what these experiences were like for them personally, as YOD nurses. During supervision, I reflected on this and wondered whether the questions I posed in this way were ambiguous. I also wondered whether questions about their personal experiences felt strange or unusual for the nurses, and were perhaps more familiar to me, as a trainee Clinical Psychologist, because I am often implicitly asking about people's personal experiences and feelings as part of my day-to-day clinical work. Interestingly, two participants commented at the end of their interviews that they had

found the process cathartic and expressed that it had been beneficial to have a space to pause and reflect on their work with people with YOD, and how this had impacted on them, particularly the emotional and personal impact of this work. One participant explained that she had never considered the impact of her clinical work on her personal life before but acknowledged that it *did impact* on her personal life, and expressed a wish to have more spaces to reflect on this. On hearing this, I initially felt pleased that participants found the interviews mutually beneficial; however, I also noticed feelings of sadness and a desire to ‘rescue’ participants or make suggestions about how they could access professional support or reflective spaces.

At times during interviews, such as when participants disclosed familial experiences of YOD, it was difficult not to move into a more therapeutic stance, and I reminded myself of the importance of staying within the researcher role, and exploring the participants’ lived experiences and how they made sense of and understood them. It was later when it came to the analysis stage, that my experiences as a trainee Clinical Psychologist felt particularly relevant. Within Clinical Psychology, time is often spent listening to people’s lived experiences, and attempting to make sense of, and understand this from our own perspectives, which felt akin to the underpinnings of IPA.

It is important to be sensitive to the socio-cultural context of the time the research was conducted (Yardley, 2000). Most interviews took place while national nursing strikes and industrial action were being planned, discussed in the media, and enacted. As topics of blurring of professional boundaries, working beyond typical hours, and feeling underappreciated, both generally, and financially, arose in the interviews, I wondered to what extent these may have been more present in the

nurses' minds, or indeed my own because of the context of the time. None of the participants directly mentioned the industrial action; however, I was aware of perhaps feeling even more empathetic towards some of the challenges the nurses faced in their clinical roles, particularly around feeling overlooked or underappreciated, because of this context.

I am looking forward to sharing the findings of this research with the participants and am hopeful that it gives voice to the experiences of a professional population who are often overlooked.

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