

**'Just because the mind is confused it doesn't mean the spirit is confused':  
Exploring the role of Anglican clergy in ministry to persons with dementia.**

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**Dementia**

DOI:

[10.1177/1471301220910572](https://doi.org/10.1177/1471301220910572)

Published: 01/02/2021

Peer reviewed version

[Cyswllt i'r cyhoeddiad / Link to publication](#)*Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):*Friedrich Jr, R., Woods, B., & Williams, S. (2021). 'Just because the mind is confused it doesn't mean the spirit is confused': Exploring the role of Anglican clergy in ministry to persons with dementia. *Dementia*, 20(2), 698–716. <https://doi.org/10.1177/1471301220910572>**Hawliau Cyffredinol / General rights**

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**Published in Dementia, March 2020**

**Sage Publications**

**DOI:10.1177/1471301220910572**

**Title: *'Just because the mind is confused it doesn't mean the spirit is confused':***

**Exploring the Role of Anglican Clergy in Ministry to Persons with Dementia**

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**Word count (main text excluding references): 5735**

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## **Abstract**

### Objectives

Churches and faith groups have an important role to play in the development of dementia-friendly communities; their support of spirituality of people with dementia and their care-givers adds an important dimension, interwoven with concepts of personhood and identity. Priests have a central role here, but little is known of their experiences of ministering to people with dementia and their families, of the challenges they may encounter, or of their perspective on dementia.

### Method

Using a collective case study approach, ten Church in Wales priests took part in an in-depth qualitative interview regarding their ministry with people with dementia. Initial thematic analysis was used as a basis for an in-depth analysis of the positions adopted by clergy in relation to dementia and those experiencing it, as well as to their roles in the wider church.

### Results

Clergy described *discovering ways of working* with people with dementia, learning 'on the job', and, for example, finding familiar symbols and music helpful. They found themselves *being an intermediary*, between people with dementia and God, but also within families and other care settings, such as care homes. *Promoting spirituality within personhood* was a fundamental aspect of their role, but was also reflected both in fears of dementia and in identifying redeeming aspects of dementia. They described an absence of *preparedness, training and peer support* for this ministry. The emerging model of dementia ministry reflected the dynamic interplay of

positions adopted by clergy, with an interface between the professional and the personal at its centre.

## Conclusion

The study indicates the need for increased support for clergy in taking forward dementia friendly churches and highlights their role in ensuring that the spiritual life of people with dementia can be maintained and supported.

## Introduction

The importance of developing dementia friendly communities is now well established, forming one of the targets of the World Health Organisation's global dementia action plan (WHO, 2018, p8) and presenting a visible indication of the paradigm shift towards recognising the citizenship of people living with dementia (Lin, 2017). Within the discourse on what constitutes such communities (Lin, 2017; Alzheimer's Society, 2017) and how best to generate and sustain them (Alzheimer's Society, 2017) the importance of dementia friendly churches has emerged (Friedrich & Woods, 2016; Adams & Anthony, 2016).

Arguably, a consideration of Dementia Friendly Church must extend beyond the wider context of dementia friendly communities and encompass issues of spirituality, person-centredness, personhood and identity. Dementia has been described as a "theological disease." (Keck, 1996; Goodall, 2011) since it raises fundamental questions about the nature of what it is to be human and the intricacies of spirituality (Goodall, 2011). People living with dementia writing about their own spirituality in relation to dementia draw attention to the role of memory and loss of self in the person's continuing relationship with God (Davis, 1989; Bryden & MacKinlay, 2003) resonating with Kitwood's (1997, p.69) recognition of the relationship between spirituality and personhood. He argues that spirituality is to be found in deep, close relationship between the person with dementia and another. Those with a concern for the spiritual well-being of the person with dementia – whether family, friend, church-worker or priest - accordingly have a challenging role, supporting the person's life story and identity, remaining close to them throughout the dementia journey (Norris & Woods, 2016).

Several studies have sought the views and experiences of clergy or church leaders regarding dementia, through focus groups, interviews and surveys. Among themes emerging

from these studies, across different denominations and countries, perhaps the most striking is that, in relation to supporting people with dementia and carers, clergy often report feeling under-prepared (Plunkett & Chen, 2015; Tompkins & Sorrell, 2008), experience worries about their own competence (Kevern & Walker, 2013) or feel insecure, or even fearful, relating to the perceived unpredictability of people with dementia (Kennedy et al., 2014). These concerns led to a perceived need for further training and support from others, with a role for clergy in supporting others in their churches providing 'hands on' support (Kevern & Walker, 2013; Tompkins & Sorrell, 2008). The majority of the clergy (55/66) surveyed by Kevern & Walker (2013) were involved in some way in supporting people with dementia and carers, and studies agreed that churches have a significant contribution to make, through, for example, pastoral visiting, forms of religious service and support for carers (Kevern & Walker, 2013; Kennedy et al., 2014; Plunkett & Chen, 2015). Positive experiences of worship services are reported by those interviewed by Kennedy et al. (2014) including positive effects on the well-being of the person with dementia, with familiar hymns and prayers and sensory cues, such as candles, music and the priest's robes seen as helpful in engaging people with dementia.

The role of churches (and priests) in wider communities is also relevant. This study focuses on Anglican churches in a setting where they may often be seen as a focal point for the community. It seeks to develop a model of dementia friendly ministry based on a series of in-depth interviews with Anglican (Church in Wales) clergy. These explored both (i) the role of clergy in supporting people living with dementia and their families and (ii) how they approached the phenomena of dementia in their ministry.

## **Methods**

The study adopted a collective case study design (Stake, 2005) which is well suited to a naturalistic approach, focused on understanding “experiential knowledge” and the “ordinary” (p.445 ). In this way: "The methods for case work actually used are to learn enough about the case to encapsulate complex meanings” (p.450 ). In this context the ‘case’ was defined as Anglican priests practising within the local area served by their church(parish) and engaging with people living with dementia and their families. According to Stake (2005), analysis of the collective cases can be developed further by theorising based on a comparative approach with reference to a broader collection of cases; however, in the first instance, the primary goal of a collective case study design is the selection of cases that provide a range of characteristics that are defined by variety, yet are purposeful enough to explore the phenomenon and research questions (Stake 2005). In this study the ‘cases’ were drawn from two of the six geographical regions of the Church in Wales (dioceses), and recruited to reflect diversity in age, gender and years of experience as a priest. Data collection in collective case study is iterative and dynamic focused on gaining access to storytelling, in order to balance the “case telling its own story” yet also “explaining issues” (p. 456) focused on rigorous analytic procedures and the triangulation of accounts. The process of analysis in collective case study work is underpinned by comparison and ‘teaming’ which involves a number of researchers (in our instance, the research team, BF, BW, SW) engaged in an integrated approach within and between cases. This requires negotiation about the ‘paring down’ of key elements of the cases to” what can be comprehended by the “collection of the team members” (Stake 2005, p. 453). In essence, the case study approach is focused on establishing boundaries around the case, identifying relevant patterns of data that can be interpreted which can be subsequently matched with the triangulation of a range of sources; as part of the analytical process it requires the researcher to explore alternative

explanations and generate “assertions or generalisations about the case” (Stake, 2005, p. 460).

The qualitative fieldwork was completed by the first author (BF), a priest completing a doctoral study, with ethical review from the Bangor University School of Healthcare Sciences ethics committee. The purposeful sample (Stake, 2005) were Anglican (Church in Wales) priests who were interviewed in 2015, recruited from the two dioceses in North Wales, UK, with the permission, and assistance, of the respective bishops (the senior priest heading a diocese). Various means of diocesan communication (clergy mailings, diocesan news) were used to give the bishops’ endorsement, encourage participation, and distribute the project description and consent forms in English and Welsh. Ten participants (5 female, 5 male) opted to take part, with ages ranging from early 40s to mid 70s, and the period of time since becoming priests (ordination) ranging from six to 43 years.

Semi-structured interviews (see Appendix I for the topic guide) began by examining aspects of the participant’s career e.g. how many years since their ordination, before going onto their knowledge of dementia, any training they had received, any experiences of dementia in their personal life and their experiences with people living with dementia and their carers in their parish. The interview also discussed the nature of their work across a range of settings, from the homes of people living in the parish, whether or not regular church-attenders, to care homes to churches. A particular area of exploration was identifying facilitators and barriers to effective dementia ministry and whether they considered their work had made a difference to people living with dementia and/or carers.

The length of the interviews ranged from 60 to 90 minutes, and took place in the participant’s office or other convenient private location. Interviews were digitally recorded for later transcription and entry into ATLAS.ti qualitative analysis software. A form of

thematic analysis (Braun and Clarke, 2006) provided an initial wave of insights into the data, through detailed coding procedures to generate a series of themes including relational dimensions. This was then supplemented by a second wave of analysis using Positioning theory (Allen & Wiles, 2013; Davies & Harré, 1990; Harré & van Langenhove, 1999). It views the dynamics of people's cognitive schemas by examining how they relate to social action and agency (Barnes, 2004). All actions are considered in relation to situational and contextual references, disclosed through how discourse is framed, reflecting positions that include embedded moral rights and duties (Harré et al., 2009). Within positioning analysis meanings are derived from the interrelationship between beliefs, social practices, rights and duties embodied in individuals' cognitive schemas. These result in 'positions' which are mediated by a dynamic social process of interaction which is sensitive to both context and temporality. These processes of meaning construction and reconstruction, positioning and re-positioning are visible through analysis of storylines within discourse (O'Connor, 2007; Harré et al., 2009). The study used positioning analysis to build a model that represented the complexity of how the clergy related to (a) the phenomenon of dementia, (b) people living with dementia and their families, (c) how they understood their pastoral and spiritual roles and (d) their role in the wider church.

## **Findings**

The thematic data analysis highlighted a range of themes that captured the constructions of participants, delineating how they understood dementia and responded both to the phenomena of dementia and people living with dementia in their ministry, as well as defining their role as priests relating to a community. Four overarching storylines emerged from the clergy accounts, under which themes could be clustered, mapping the supporting acts,

actions and processes involved in the clergy's ministry to people with dementia (see: Table 1). These storylines will now be outlined, prior to a consideration of their wider context as part of the model of 'dementia ministry', drawing on the positioning analysis.

Table I Emergent insights: framing a dementia ministry

Storylines	Themes	Description
<b>Discovering Ways of Working</b>	<ul style="list-style-type: none"> <li>• Experiential learning</li> <li>• The impact of creativity and music</li> <li>• Working with symbols and tangible objects</li> <li>• Ministry of Laity</li> </ul>	<p>This storyline and themes detailed the importance of experiential role of clerical practice in developing appropriate and at times creative responses to dementia within the congregation, working to engage people living with dementia using a range of methods and techniques. This involved working across diverse settings. The leadership role of the clergy was vital in providing a cue for communities and increasingly supported by laity involvement in ministry and pastoral care.</p>
<b>Being an Intermediary</b>	<ul style="list-style-type: none"> <li>• Interceding between people living with dementia and God</li> <li>• Intermediary with families and communities</li> </ul>	<p>This storyline and themes identified the clergy’s acts and actions as ‘intermediaries’ between people living with dementia and God, maintaining an important role as with other parishoners but extending the repertoire of methods to maintain this relationship. Also they acted as intermediaries between people living with dementia and families and the wider community. The liturgy provided a key resource for bridging the spiritual relationship between people living with dementia and God as well as with the church</p>

	<ul style="list-style-type: none"> <li>• Intermediary in different settings: In church, care homes and families</li> </ul>	community. The role of intermediary was difficult at times for clergy to accomplish and in care homes there were particular challenges and rewards.
<b>Promoting Spirituality within Personhood</b>	<ul style="list-style-type: none"> <li>• Seeing personhood and spirituality in people living with dementia</li> <li>• Fear of dementia</li> <li>• Redeeming features to dementia</li> </ul>	This storyline and themes centred on the clergy adopting a positive view of dementia, asserting the presence of personhood and the spiritual self, despite disease. There was fear of developing dementia in the future but also a naïve view of dementia built on forgetfulness, that identified redeeming features of dementia based on the person lacking awareness of their situation.
<b>Preparedness, Training and peer support</b>	<ul style="list-style-type: none"> <li>• A lack of training from before ordination</li> <li>• Sense of isolation and learning by experience</li> <li>• Materials to support worship</li> </ul>	This storyline and themes highlighted that clergy required more substantive preparation and training for their pastoral and spiritual support for people with dementia. Currently there is a lack of support and training, leading to a sense of isolation although priests have developed innovative ways of working. Tuition is required at seminaries prior to ordination and on an

		ongoing basis, with particular reference to care homes. Reflections on materials to support people living with dementia may also be useful.
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### **Storyline: Discovering Ways of Working**

Overall, there was an absence of formal training or preparation resulting in the clergy discovering what was best practice inductively. It involved 'bottom up' innovation based on experiential knowledge and developing intuitive practice. Participant 2 acknowledged that he was *'learning a lot on the job'*.

People living with dementia were said to generally relate positively to clergy, particularly those wearing symbols of priesthood:

*"I think if they see a clerical collar it awakens that spirituality in them" (Participant 6).*

This applied to a number of settings, both operating in people's own homes as well as within the confines of the church and services:

*"I find it helpful if I'm going to take a service or something to wear my robes. It seems to jog peoples' memory" (Participant 8).*

The clergy identified that people living with dementia connected at some level with their presence, recognising a linkage to a sense of attachment and pleasure, although this was surprising for some of them and unexpected:

*"Maybe the collar helps, I don't know...although they are losing it mentally they are still very happy, very pleased to see you...there is still that smile and appreciation" (Participant 2).*

Music as well as creativity was an important theme. Five participants recounted that music, especially familiar hymns, triggered memories for people living with dementia. The use of music included examples of creativity and innovation, so as to create contexts for stimulation of expression of spirituality to occur.

*“We started [an open afternoon], the church could be open and you could provide some refreshments and I can organise a choir ... people came in from the local older people’s homes as well as individuals with their family carers, and I sat talking to this lady who must have told me in the course of our conversation 15 or 20 times: “I didn’t want to come you know. I’m not well. I said I’m not going to come.” As soon as the choir started singing she knew the words to every carol and every Christmas song, and she stood up and she performed. She was 80 something, and afterwards her daughter was in tears. Her daughter said; “I didn’t know my mother could sing. I’ve never heard her sing.” And the music actually turned that person with dementia into a person again” (Participant 7).*

The nature and temporal framing of the music was nonetheless important, linking it to biographical anchors, and the clergy noted how important this aspect was for success. It highlighted for them how people with dementia could retain a spiritual positioning, although this position was temporary, dynamic and fleeting it was nevertheless significant. Developing this approach to bridging the barriers to spiritual expression resulting from dementia was important:

*“That sort of hymn - Blessed Assurance, O Jesus, I Have Promised, that sort of...none of the modern choruses. I can do modern choruses, but in this setting it was important to try and trigger memories and engage at that level. So really old fashioned stuff: and you’d be amazed how many of those experiencing dementia were able to join in...it was a touching and an engaging again with God for a moment or two” (Participant 1).*

It was clear that clergy discovered not only ways of working with people living with dementia but also realized the value of people living with dementia being part of worship, being positioned beyond passive recipients of ministry but creating significant moments within it. This was best exemplified by Participant 8, again associated with the thread of impactful music combined with spirituality:

*“And he was in this same nursing home in \_\_\_\_\_, and I went there just before Easter... and we sung the hymn When I Survey the Wondrous Cross. We sang it in Welsh, and we had somebody playing the organ, and this man... has a lovely voice, and he remembered the words of this hymn. But when we’d finished singing he hummed quite loudly the next verse, and it was all absolutely quiet. It was one of these real spiritual moments. And everybody in the room - there were twenty plus people there - absolutely quiet. And when he’d finished singing it was still quiet. And I let it be quiet for a bit” (Participant 8).*

The impact of symbols and objects, in worship for people with dementia was noted, encouraging engagement and re-connection:

*“I used to take things like bells...to use at communion. We would light candles. I would invite people to come with their carers, to come and light a candle in memory...”*

Clergy identified through their experiences the importance of leading within their church the best approach towards inclusion of people with dementia, maintaining their connections with the familiar representations and signs of their faith, as well as taking part within worship. The discovery of different ways of working focused on recognising the individual people living with dementia as requiring spiritual ‘nourishment’ as with any other member of the congregation:

*“I think if the day came that we sat him down in a corner and said: “don’t worry we’ll do everything.” I think then he would begin to lose not only his dignity, but... to some extent his faith wouldn’t be quite as well nourished... And I think in doing the things he’s always done in his own church he’s getting the nourishment he needs.” (Participant 6).*

Such leadership led to acceptance by the community with responses being positive, perhaps “one or two little smiles and little embarrassments” (Participant 1) but acceptance and an increased knowledge of dementia. Indeed, the role of the clergy was increasingly supported by ‘ministries of laity’. Three clergy identified the significant role played by members of congregations enacting a proactive approach to drawing in people with dementia as part of their local community, built around the priest but extending the scope of pastoral care and support:

*“We have one person who really wants to focus on that side of things because her mother suffered from dementia problems. She feels a calling to that ....so she’s taken over a lot of the responsibility for going into care homes and nursing homes. Which is great” (Participant 2).*

### **Storyline: Being an Intermediary**

The clergy were positioned and position themselves in a dynamic role as an ‘Intermediary’. This focused on acts and actions firstly between those with dementia and those without, including carers and social services, congregations and wider communities / society, as well as secondly maintaining their relationship with God through active ministry. The latter was

particularly important although complex and less visible than being an intermediary to families and communities. As such priests reflected on how they interceded between people living with dementia and God, as they would with all parishioners but through more discrete and innovative actions:

*“Maybe you don’t have to be talking all the time when you have a conversation and maybe just sit there in the silence, in the presence - and personally I don’t find that easy... There is that desire or expectation that you’re talking about it, what’s happening, what Mrs. Jones is doing...and that doesn’t really work anymore. So maybe to learn how to be comfortable in the silence” (Participant 2).*

Three clergy noted how they deployed reminiscence as a spiritual tool:

*“I think an openness to try to keep their lives as normal as possible and a support in the sense that you try to connect with them with things that they can still identify. Events that have gone on in the past, events in the family, showing them photographs and that kind of thing” (Participant 9).*

A key framework for being an intermediary in a spiritual relationship between people living with dementia and God was the use of liturgical prayer, not only as a powerful trigger for memory for people living with dementia but also reconnecting with a continuity of spiritual observance and meaning. For older people, it needed to be in the familiar language of the Prayer Book they grew up with and represented a key mechanism which clergy could use for bridging the experience of living with dementia and re-enacting the biographical connectiveness to God. For instance, the act of communion could be a trigger for engagement, recognition and a touchstone of spiritual connection:

*“ Actually seeing the bread and the wine will bring it back to people” (Participant 8).*

The liturgy as a set of language, codified with its rhythm, longitudinal familiarity and symbolisms and signs provide a rich resource:

*“The Lord’s Prayer is something that is instilled in them so much...are the words so familiar that it reassures them? I think so. And I think that our worship, for them, has got to be something that actually takes them back, or something which is so part of them that it comes alive again whereas the rest of it...but they know...they receive the bread and the*

*wine and say the Lord's Prayer...maybe an occasional "Amen," but am I tailor making that worship for them.? No" (Participant 7).*

Importantly, clergy had to be sensitive to ensuring the language resonated not with modern editions but remained biographically sensitive as part of their ministry and yet even in advanced stages, the connection between liturgical phrasing and people living with dementia remained:

*"the husband, had dementia, and when he really became quite bad he stopped coming to church so I took church to him if you like. I took communion to him at home...he used to be able to say the whole of the responses for the communion service himself. But as time went on he needed to be prompted. His memory gradually faded, and yet for some things he would remember such as the Lord's Prayer" (Participant 9).*

Yet the role of being an intermediary was difficult and five participants reflected on its problem areas, admitting they found working with persons with dementia difficult. In care homes there were mixed expectations from staff viewing clergy either with a degree of resistance or merely as someone to engage in 'reminiscence', yet it remained an area where there was a unique contribution of extending the relationship with God and the church community within the care home:

*"It's a smallish home with a family atmosphere, and they were extremely good. I used to go in with communion. That's an experience and a half...You have to be prepared for anything. Anything said. Anything done in the middle of a service. (laughter) If you've got a sense of humour, it's fun. And if you frown easily I don't think you could cope with it" (Participant 6).*

However, some clergy found being an intermediary highly problematic, especially as the dementia progressed, from their own point of view and family members and laity:

*"It doesn't feel as if you're having a meaningful relationship with them anymore because...they've almost disappeared, they've almost...their mind is gone. And people struggle to know how to cope with that." (Participant 2).*

### **Storyline: Promoting Spirituality within Personhood**

The clergy were clear about the importance and presence of personhood in the people with dementia they served. Recognising personhood was a dominant theme within the

interviews, with participants articulating that people living with dementia should be treated equitably along with other parishoners experiencing illness as part of their lives:

*“It is about relating to that person made in the image of God. I think what has been helpful is holding fast to the fact that they are a person still and that we should not treat brain disease in any way different from the way we would treat cancer.... You know with the person with cancer we don’t regard them as a non-person. Dementia...they’re still a person...made in the image of God - seems to be we need to remind ourselves.”*  
(Participant 7)

Relating to persons with dementia as persons was the mechanism for promoting spirituality for five of the clergy. The challenge was developing a strategy that enabled it ‘to work in practice’. The central role for clergy was seen as finding personhood amidst the ‘cloud’ of dementia:

*“somewhere under that sort of cloud of mental confusion is a soul. And so we try to still reach that soul with the Spirit of God within”* (Participant 1).

There was a clear stance adopted by clergy that dementia should be understood as obscuring the spiritual life and personhood of people living with dementia rather than removing it:

*“if we aren’t careful because the mind is muddled we think that the spirit is muddled. And very often it isn’t.”* (Participant 8).

Although the clergy adopted a positive and proactive approach towards dementia and personhood there was much reflection about developing dementia oneself, thoughts that triggered existential questions about life itself. Most of the clergy interviewed had given considerable thought to this, and five expressed clear fear about it. Despite their positive view of people living with dementia, for them the root of fearfulness was the challenge of dementia to personhood and their sense of identity, Participant 4 stated:

*“I’d rather have cancer than dementia”*

whereas Participant 7 highlighted the scope of fear which extended beyond themselves but to wider family:

*“I’m frightened of it. I’m frightened that it might be happening to me. I’m frightened that it might be happening to someone close to me”* (Participant 7).

The exposure to dementia within their communities and engaging in ministry with people living with dementia triggered fears around general memory loss:

*“You think if you start to forget things: “Oh dear, is this the first sign?”* (Participant 8).

A particular concern was the process of dementia and its gradual impact within daily life:

*“It’s that period in-between where you know you’re forgetting things that must be the most difficult. And I think that’s the bit that I would fear rather than being gone completely”* (Participant 6).

Yet amongst the clergy sampled three expressed little or no fear and all but one highlighted redeeming features to dementia from their experiences. Their perspective was complex and at times contradictory, centred on their construction of dementia as solely focused on ‘forgetfulness’. The redeeming feature of ‘forgetfulness’ appeared to be that if it went far enough, then the person was seen as forgetting their difficulties and potentially entering a place of happy release. Having lost awareness of difficulties, then the person was seen as “*beyond...beyond knowing*” (Participant 4) and therefore freed from responsibilities and suffering, such as grief and loss, being “*in a world of your own*” (Participant 4). It seemed from the interviews that the participants were seeking to understand the phenomena of dementia through the lens of their experiences, attempting to extend their understanding from individual cases and drawing wider conclusions, reporting fear and potential redeeming

features of forgetfulness with uncertainty, asking “Does that make sense?” (Participant 4). A recurrent theme was a viewpoint focused on personhood and the spiritual self:

*“I think it presents people as they are. If we’re all on a journey and then the dementia is part of that journey ... the redeeming feature is that even though there is brain disease it is still a person made in the image of God.” (Participant 7).*

### **Storyline: Preparedness, Training and peer support**

Participants described the task of clergy within communities as often involving a vertical and horizontal relationship, that is within their communities and with God. All participants had developed their own ways of ministering to people living with dementia, ‘on-the-job’ employing experiential and intuitive learning, focused on being creative and with a strong sense of delivering pastoral care. There had been no opportunities for any formal training or support for working with people living with dementia and their families, or in understanding dementia, prior to ordination or subsequently:

*“And certainly when we came to training for ordination there was nothing at all on ministering to people with dementia” (participant 1).*

Indeed, there was very little in terms of preparing clergy for pastoral care that could be applied to the situations encountered with people living with dementia:

*“We did a very short thing on interpersonal relationships which hardly scraped the top of the thing, because it tried to do everything” (Participant 6).*

Across all participants there was a resounding call for the Anglican church to develop increased preparedness for dementia ministry:

*“Yes, so it’s incumbent upon the church to equip the clergy who should be at the front line of this” (Participant 4).*

The wide range of years since ordination in the sample resulted in some having been ordained many years ago:

*“Dementia was not something which was very visual or being talked about [then]”*

(Participant 5).

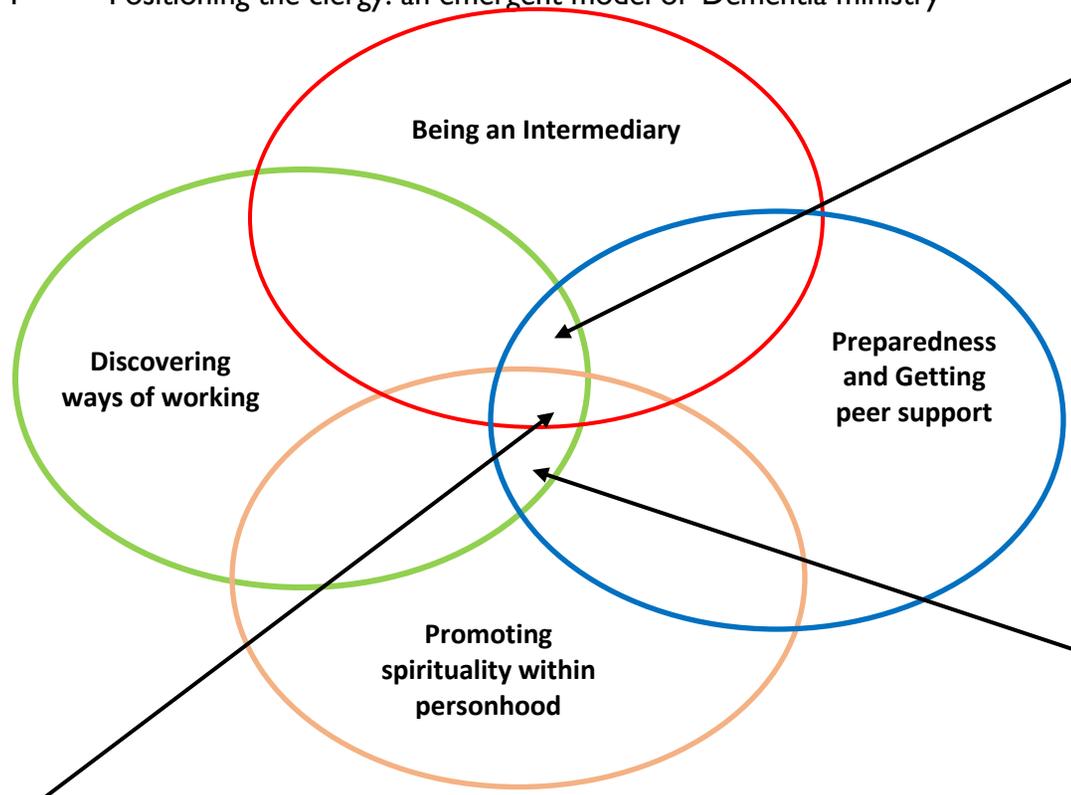
A specific area of concern was preparation for ministry in the care home sector with its numerous challenges, distinct from people’s own homes and the setting of the church:

*“there should be training in how to cope with various aspects of health, mental health among them”* (Participant 6).

Further, the area of resources was identified as relevant to equip clergy in their ministry for people living with dementia, with a need to provide bespoke material for priests to assist with designing worship:

*“Well if I was to do a service specifically for people with dementia probably have a couple of hymns and I’d do a reading and we’d say a few prayers”* (Participant 2).

Figure 1 Positioning the clergy: an emergent model of 'Dementia ministry'



**Professional domains**

Area of formal practice developed across different settings, groups and people with defined role as clergy within communities. Focus on position of 'Embeddedness' and 'Encountering'.

**Personal domains**

Informal and 'Bottom-up' area of practice, with innovation based on experiential knowledge and intuition. This centred on the positions of 'bridging' and 'signalling'.

'Dementia ministry' centred on the interrelationship of the four storylines evidenced in the data, representing the platform for framing what may be a 'Dementia Friendly church' within communities



## Synthesis: A model of ‘Dementia ministry’

The findings from the qualitative interviews highlighted the complex positioning adopted by clergy in the study, mapping the hidden interrelationship between clergy, dementia as a phenomenon, people living with dementia, the families of people living with dementia and the wider church. The series of important storylines uncovered in the data from the themes and positioning analysis (Harre et al., 2009) led to the development of a model to convey the dynamic nature of the experiences narrated by clergy representing the key elements of a ‘Dementia ministry’, shown in Figure 1. At its core was the interrelationship between these storylines generating two distinct domains within which ‘dementia ministry’ operated, respectively at a ‘professional’ and ‘personal level’. These were associated with four main positions identified as being adopted by the clergy (see: Table 2).

Table 2 A ‘Dementia ministry’: dynamic Positions

<b>Positions</b>	<b>Description</b>
Encountering	This position built on professional experiences by individual clergy of people living with dementia. It constructed a narrative, an understanding and resulting discourse that shaped daily pastoral and spiritual life of the clergy and framed their approach, in the absence of training.
Embeddedness	This position reflected the way in which the professional role of clergy was embedded within particular communities, with set boundaries regarding how they operated as intermediaries between people (individuals, families and wider communities) and God. As part of the intermediary role they utilised formal symbols and artefacts to engage with people with dementia and offer pastoral care to them.
Bridging	This position was focused on safeguarding personhood and a relationship with spirituality and God. It was built upon personal experience driving forward ministry and drawing

	together personal and professional aspects of being a priest but based on a belief in locating actions in valuing personhood.
Signalling	This position was centred on acknowledging the continued presence of God in the lives of people living with dementia despite the presentation of dementia and motivated by personal belief seeking to underpin their ministry by this part of their daily life as clergy, in some instances accompanied by personal fears of the development of dementia.

In practice there was a dynamic relationship between the professional and personal domains (see: Figure 1) to construct a ‘Dementia ministry’ in day-to-day life. The ‘professional’ domain hinged on the specific role of the Anglican clergy within their local community and the church, reflecting a position of ‘embeddedness’. As such, the clergy operated as formal intermediaries (*Being an intermediary*) within families, between family members and the people living with dementia, supporting both in terms of adjustment to challenging circumstances as part of a pastoral role. However, the intermediary role also formally acted between the spiritual life of the people living with dementia and the phenomena of dementia. The potential dissonance was structurally bridged by using hymns, symbols and other artefacts to continue to engage and re-engage people living with dementia with their spirituality and foster a continuing relationship with God in terms of continuity with their family members and wider church community. As part of the professional domain, the *Discovery of ways of working* was focused on the importance of experiential learning of daily pastoral and spiritual life of the clergy. Their ‘bottom up’ experiences accumulated through formally ‘encountering’ the presence of dementia as well as people living with dementia as a feature of their role as priests and parish life. It was noteworthy that there was a clear sense of isolation by the clergy from the wider church, with skills and approaches developed from ‘trial and error’ with the absence of preparedness of the clergy through support and training from the church as an institution (*Preparedness and Getting peer support*).

The 'personal domain' in contrast represented the interior and informal world of the individual clergy, including personal characteristics of the clergy themselves that drove forward efforts to engage with dementia and people living with dementia. It was evident that for 'dementia ministry' to occur the substantive motivation was indeed personal, in the vacuum of formal training, mechanisms or peer support, with *Promoting spirituality within personhood* being at the core of supporting the clergy's actions. This was the recognition that a relationship with God was about continuity that was not precluded by the onset and continuing effects of dementia. An awareness of personhood was a central part of the clergy's ministry and built into their personal way of working, recognising and responding to individual biography and thereby being a position of 'bridging' dementia to secure continued spiritual life. Through their personal domain the clergy reinforced a formal 'intermediary' role in their continued spiritual-orientated contact with people with dementia (in addition to pastoral responsibilities) and adopted the position of 'signalling' the continued presence of God shared with the person with dementia:

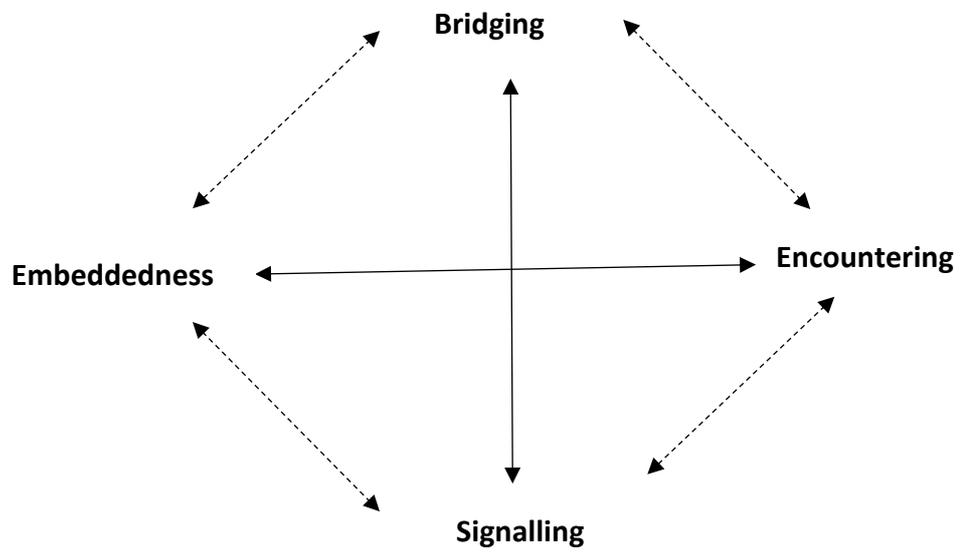
*'I know it sounds a bit cliché but this is another child of God who God loves, and because of their illness they're not able to respond or communicate as other people can.'* (Participant 10)

'Signalling' also had a personal dimension, in relation to the fear of developing dementia that a number of participants expressed, making the need to hold onto the sense of continuing connection with God even more pressing.

As part of the model of 'Dementia ministry' (Figure 1) the interface between professional and personal domains was a key feature and it was evident that much more support and training was required to underpin the development of a 'Dementia ministry' in practice. However it was also apparent in the data that major opportunities were present, highlighting how clergy themselves constructed important mechanisms for framing Dementia Friendly Church and a positive experience for people living with dementia based

on four positions that were generated at the personal / professional interface. These positions were pivotal in developing a positive experience of a 'Dementia ministry', representing drivers for potential action, based on the reciprocal relationship between professional and personal domains, arising from the four storylines discussed above. In this respect these positions represented a dynamic quadrangle as part of the daily life of clergy (Figure 2) framing their social actions and discourse towards people living with dementia, families and the community, blending together the personal and professional. We describe this as dynamic, in the sense that clergy do not adopt one position or another, but move rapidly between them or blend different positions as the situation demands. As with any other professional, there will be an interaction or even tension between professional and personal domains, complicated perhaps as, in this instance, the spiritual dimension is expected to be central to both.

Figure 2 A Positive quadrangle: Positioning of clergy for 'Dementia ministry'



## Discussion

Whilst pointing out there is no single template for a dementia friendly community, Lin (2017) highlights one model encompassing four cornerstones: places, people, resources and networks. Churches and other faith communities can be seen as providing a building, a place, where attention needs to be given to the physical environment; as a community resource, providing services which should be inclusive of people with dementia; and also as a core member of wider community networks. Faith communities that offer support to people living with dementia have been described as “An embedded presence in communities, with the ability to link with other people and organisations locally to help build a dementia-friendly community in the wider sense.” (Faith Action, 2017, p.4).

Faith communities may not be unique in having multiple roles within the dementia friendly community movement, but unlike banks, supermarkets or transport organizations, their involvement is predicated on an understanding of spirituality and dementia. In this study the focus has been on the case of Anglican clergy and how the development of their ‘Dementia ministry’ is complex, not least because of their perceived role as an intermediary between people living with dementia and God. It is clear from the findings that understanding what may represent a ‘Dementia ministry’ is important and requires careful scrutiny, if clergy are to play a role in developing a Dementia Friendly Church. This will involve ‘preparedness, training and support’ as well as discovering flexible approaches to ministry for people living with dementia, locating personhood and acting as an intermediary.

All ten clergy interviewed showed a well-developed ability to learn from the novel and challenging experience of ministering to people living with dementia and were intuitively developing pastoral strategies to provide effective ministry. The ways of working

discovered by the clergy, such as familiar liturgy, music etc. were a good fit with both the findings of Kennedy et al. (2014) from interviews with worship leaders and the experiences of continued spirituality reported by people living with dementia. For example, for the six people living with dementia interviewed by Dalby et al. (2012), it was important to maintain established spiritual practices, such as bible reading, meditation and prayer, as well as remaining part of a spiritual community. Similarly, Jolley et al. (2010) reported from a survey of 20 people with dementia from a Memory Clinic that continuing with familiar spiritual practices was a source of comfort.

Consistent with previous studies (Tompkins & Sorrell, 2008; Kevern & Walker, 2013; Plunkett & Chen, 2015), None of our sample had any training for this in their professional preparation and. A all indicated some degree of difficulty with working with people living with dementia and experienced it as a test. They found the resources for meeting the challenge within themselves as a function of spiritual growth. Personal fears of developing dementia were apparent, as well as the challenges of working in potentially difficult environments such as care homes. The clergy in the study received some limited support from peers and some from lay church members as well. They indicated a desire to achieve preparedness through formal training in ministry preparation and from ongoing church training opportunities. They were eager to spend time with colleagues and other professionals who had valuable experience to share. Peer support may often be lacking for clergy themselves, resulting in them being isolated (DeVogel, 1986). It was evident that ministry is a combination of professional and personal domains, reflecting in this context the nuanced relationship pervading clerical life (McDuff and Mueller , 2000).

## **Strengths and Limitations**

A potential weakness of the study was the relatively small number of qualitative interviews (n=10), centred on two dioceses in North Wales, potentially biased towards those with an interest in dementia, but with diversity in age, gender and experience. However, these were in-depth interviews subject to detailed analysis, with participants expressing their views with openness and candour, such as articulating isolation and lack of training. Perhaps this was facilitated by the researcher (BF) being an ordained priest, creating an environment of trust and empathy as well as framing of the interview as a 'conversation with a purpose' (Denzin, 1988). Although a strength this required reflexivity by the researcher, documented in fieldnotes and involving debriefing with supervisors.

A major strength of the study was the rich nature of the data with its thick description of hidden parts of the clergy's role and the use of positioning analysis to move beyond description towards conceptualising 'how' clergy responded to people living with dementia as well as the phenomena of dementia.

A limitation of the study is that it is conducted with priests from one religious denomination. However, examination of the themes suggests potential generalisability to other faith communities, with their own traditions of religious practices and rituals and their own understanding of the role of priest-type figures in linking the divine and the human realms. All bring the added dimension of spirituality and spiritual experience to the dementia friendly community, and their priests will face similar challenges, in relation to training and preparedness, fears and understanding to those reported here. Further exploration in other faith communities would be helpful in taking this area forward.

## **Conclusion**

The paper presents an unique lens on the complexity of developing Dementia Ministry and the importance of understanding the role of clergy themselves. It highlights that as an

emerging area in establishing Dementia Friendly Communities further attention is needed to prepare and equip clergy to provide a supportive environment for people living with dementia. The findings from the study provide a platform for mapping how to move forward by providing clarity in understanding the nuances of the clerical role, in relation to people living with dementia, families and the phenomenon of dementia. There is a clear need for training regarding dementia to be made available to priests in training as well as to those already ordained. Support for clergy, from peers and lay members of the faith community is also needed. Provision of relevant materials, service outlines etc. would also be of assistance in engaging people with dementia in religious services and practices, and as indicated by Friedrich & Woods (2016) a number of excellent resources are already available from organisations such as Livability ([www.livability.org.uk](http://www.livability.org.uk)). But the study also indicates the potential benefits for the wider community of engagement with faith communities, through their resources they may offer – of people and buildings, their ability to work across a range of settings – community, care homes, hospitals, with carers and people with dementia, and above all to bring a strong commitment to upholding personhood, through their recognition of the importance of spirituality to the identity of the person with dementia.

## **Acknowledgements**

The authors wish to thank the Church in Wales Bishops of St Asaph and Bangor and Sarah Wheat, Engagement Officer, Diocese of St Asaph, for their assistance in recruiting participants, Sandra Friedrich for assistance with transcription and all the participants for their willingness to share their wisdom and experiences.

## **Funding**

This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors. The work was undertaken as part of Bob Friedrich's PhD studies at Bangor University.

## **Declaration of conflicting interests**

The Authors declare that there is no conflict of interest.

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## Appendix I.

### **Qualitative interview topic guide**

- Demographic information:
  - age, gender, years since ordination
  - training in care of people with dementia
- What has been your personal experience with dementia?
- What is your experience with people with dementia and their carers in your parish?
- What is your experience with people with dementia and their staff-carers in residential care homes?
- What hindrances have you experienced in ministry to people with dementia and their carers?
- Have you wondered what it would be like to develop dementia yourself?
- Are there redeeming features to dementia?
- What facilitators have you experienced?
- What would help you in your ministry to people with dementia and their carers?