HOLINESS
THE JOURNAL OF WESLEY HOUSE CAMBRIDGE

Reimagining dementia: seeing ourselves more fully in the dementia-diagnosed

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How does the Church respond to the increasing number of dementia-diagnosed within our communities? This paper argues that the Church inhabits Kitwood's 'standard paradigm' of dementia, which focuses on the loss and decay of the person. This diverts our attention away from a more theologically nuanced understanding of the person and personhood. Using Lartey's Theological Form model of action and reflection, I will reflect on the pastoral experience of caring for the dementia-diagnosed and seek to promote an alternative theology of personhood as relationship based on Moltmann's 'social trinity' explored through the creation narrative of Genesis 2. This will allow us to develop an alternative model of pastoral care which enables us to see the 'angelic mission' of the dementia-diagnosed.

DEMENTIA • PERSONHOOD • PASTORAL CARE • TRINITY • PERICHORESIS

www.wesley.cam.ac.uk/holiness
HOLINESS The Journal of Wesley House Cambridge
Volume 3 (2017) Issue 1 (Holiness & Pastoral Relationships): pp. 57–69
ISSN 2058-5969

Introduction

Friends who are dementia-diagnosed have the ability to make us laugh and cry. This ethnographic study of local churches' responses to dementia has identified their difficulty in living with dementia-diagnosed friends. This is because the Church often inhabits the 'standard paradigm'[1] of dementia which focuses on the 'loss' and 'decay' of the person. Using Emmanuel Lartey's Theological Form model of action and reflection,[2] I seek to promote an alternative theology of personhood as relationship based on Jürgen Moltmann's 'social trinity'[3] explored through the creation narrative of Genesis 2.[4] Not only does this alternative paradigm recognise the valued personhood of the dementia-diagnosed but places them, along with all who are differently abled, as 'angelic missionaries'[5] to the community who enable us to recognise our own personhood more fully. When we recognise that we are angelic missionaries to one another, we inhabit that very Methodist ideal that there is no holiness except social holiness; that is, we can only become fully in God when we seek God in and through each other.

Methodology

The observations made in this article have arisen out of my own pastoral practice. The churches on which my reflection is based have an age profile that is older than their surrounding communities; in addition, the rate of dementia diagnoses within these congregations is growing. This context is not unique and the reflections in this article have a broader applicability than the churches out of which this reflection grew.

Engaging with the congregations as someone offering pastoral care placed me in a 'liminal' space, being both a part of and standing outside the group.[6] Thus my reflections are ethnographic,[7] requiring me to be open to my own biases[8] as well as others' biases towards me. At the time this study began, my mother was beginning to display the symptoms of a dementia diagnosis, which inspired a greater interest in the study that was always present in my mind when encountering the dementia-diagnosed.

Secondly, attention must be paid to the method. The genesis of my study was formed through a reflection on a pastoral conversation with Edward,[9] a man suffering from advanced dementia. It quickly became clear that responding to his dementia was part of the sacred narrative of Edward and his family and friends, in which this response was intricately woven together with their personal experiences of the condition. I considered that the most appropriate way to gather data to enable deeper theological reflection was through further pastoral conversations with sufferers, their carers and those within the congregation who offer pastoral care. These conversations form much of the evidence used in this article.

A theological reflection on how a local church can engage with dementia sufferers using Lartey's Theological Form

Starting with an experience with Edward

Edward gripped my hand as I tried to lead us in prayer. Edward, suffering with dementia, displayed signs of unease by my presence and showed no recognition of me or what I was saying. As I reflected, I began to question whether my pastoral care approach to Edward, and several others who suffer with dementia in various stages, was adequate, appropriate or life-affirming for any of us. I find each sufferer difficult to visit. Is this, I asked myself, because of the anticipated chapters in my own living document that will encounter dementia? Or is it a case of needing to learn a new set of skills? Or is it because the narrative I am inhabiting, and helping to write, concerning dementia-related issues might be incongruent with the lived experience of Edward and others.

Situational analysis – the narrative so far and its informants

To identify a narrative to inform future practice, it was important first to explore the local churches' espoused (that is, what they say they do) and operant (that is, what they actually do) theologies[10] and praxis concerning dementia. Brian told me about his wife Rita, who is in the advanced stages of dementia. He said that he did not visit her often because he had already 'lost' her and he grieved for her as though she had died. The voice of bereavement is loud within the congregations I studied, and is supported by other observational comments, such as 'Edward is not the Edward we knew'. For many, this is how the harsh realities of dementia are described. Jon Stuckey writes that Alzheimer's, a form of dementia, 'can steal memories … personalities … [and] bodily functioning'.[11] The loving person we remember has been transformed into a dependent person robbed of the personality we once loved.[12] The individual has become a stranger.

But is loss the only narrative? Christine Bryden, a dementia sufferer, challenges this experience of the loss of self when she asks, ‘Exactly at what stage do I cease to be me?’[13] Bryden determines herself differently from the definitions and assumptions made by those who view her disease as robbing her of herself.

The transition from friend and lover to stranger is reflected in the reaction of the congregation to the changing person before them. When Edward is present I see that he is largely unacknowledged. Congregants speak to his wife Lisa about him but are reluctant to speak with him. It is as though Edward might exist elsewhere but the person before them is a stranger. One person told me their reticence to speak was because they didn’t think they should try talking to him because he was a stranger and he wouldn’t understand anyway. In another situation, a man will talk for his wife, who is in the early stages of dementia, even when she is addressed directly. For many, this reluctance stems from a fear of interaction. There is a fear of upsetting them, causing them stress, or of receiving an unexpected reaction. For the most part, personal interactions in the church community are predictable, but dementia makes them less so.

There is a broad body of literature and range of organisations helping to raise awareness and engagement with dementia-care issues from which churches can draw. This should be embraced and celebrated. For example, the charity Livability has a ‘dementia-friendly church’ initiative[14] and MHA have published guides on pastoral visiting and worshipping with dementia sufferers.[15] Such literature seeks to change the operant culture of engagement through the use of space, imagery, language and welcome. On one level such initiatives will help to include Edward and they encourage the church to offer ministry that allows the dementia-diagnosed to know that they are embraced by a loving and caring God. However, they are frequently interpreted by congregations as forming carer–client relationships where the role of the carer is to convince the dementia-diagnosed that God holds them rather than enabling a natural sense of a mutually growing community.

The issue of the kind of relationship we are creating comes into sharper focus when we feel we must measure our success by the reaction we get. For example, a group from a local Methodist church visit a care home for the dementia-diagnosed once a month. They sing hymns, read Scripture and pray. Often, in the chatter on the way back to the car park, the group assess whether the session was good or not by how much ‘interaction’ they had encouraged through the singing. If no one joined in they wonder about the value of what they are doing. If the residents are particularly disruptive that week, then members of the local church can feel their time has been wasted. Do we only think we are successful if we notice that residents recognise the hymns or if they sit and listen intently? If we do not see such a response, we feel that our initiative has been ineffective and wonder if there is any value in continuing.

In other conversations, we discuss the frequency of taking extended communion to dementia-diagnosed members, often revealing a reticence because 'they can't participate'. Exclusion can arise unintentionally because of the expectation that the inclusion of the dementia-diagnosed is the sole responsibility of specially trained members of the congregation, or from the assumption that it might be more appropriate to engage with the dementia-diagnosed through specialist groups.

To my mind, many of these perspectives on the dementia-diagnosed derive from a powerful but misappropriated definition of dementia. Dementia, we are told, is a progressive disease in which brain cells die, leading to mental and physical loss of function.[16] The World Health Organization says that this makes a person 'progressively different and less able as they lose the ability to retain new information or recall previous memories, even of close relatives, together with loss of cognitive ability and changes to social behaviour'.[17] These medical symptoms make friends with dementia unknown and unpredictable, which in turn makes our attempts at integration difficult. Swinton argues that our expectations of the dementia-diagnosed are constrained by such definitions, which support Kitwood's 'standard paradigm' of dementia, which always focuses on the *loss* of dementia and in which we often fail to recognise the *person* who is dementia-diagnosed.[18]

Re-examining our theology

The stark realisation from this is that our operant theology of dementia is one of decay and death, given prominence by the power of the definitions associated with dementia. Our pastoral response focuses on the family and carers of a dementia patient. There is little mention in this theology of 'resurrection', and the voice of hope is silent. Peter Kevern observes, when asking the question of where God can be found in dementia, that dementia represents a 'slipping away'[19] of personhood. This presents a challenge to theology: how do we recognise personhood? What is it and can we find it in dementia?

So, what is personhood? Often, we recall someone by remembering their 'something' and thus define 'persons' by what they *do* rather than the *human* who displays those properties.[20] The Australian ethicist Peter Singer argues further that personhood is functional, reliant on an awareness of self, context, relationships, communication and curiosity.[21] With this functional definition of personhood, when the patient has no function they are no longer a person. This is a bleak perspective on personhood and in condemning the dementia-diagnosed it raises analogous questions for the newly born who might also be relegated as non-persons according to Singer's definition. Given that the Psalmist declares that each of us is fearfully and wonderfully made, knitted together in the womb,[22] is there an alternative notion of personhood that derives value despite function?

Bernd Wannenwetsch argues an alternative paradigm is found in the second Genesis creation story, in which Adam only becomes aware of himself when he relates to Eve; he cannot conceive of himself without Eve. Adam could not have gained such self-recognition through his relationship with the animals under his dominion. Wannenwetsch argues this is because only Eve was of Adam's bone and so only Eve could reveal what humanity is, and enable Adam to recognise himself.[23] Phyllis Trible makes the point that the Hebrew *'adham* is often translated as *Adam* in Genesis 2 but *human* in Genesis 1. Therefore, Adam begins as a creature embodying both male and female and only becomes a man in the paradigm of man and woman.[24] Personhood is not, then, an objective characterisation but rather a subjective and relational concept. Kitwood argues that our personhood depends on relational recognition of self with the other.[25]

This relational approach is a rich theological seam. In *The Trinity and the Kingdom of God*, Jürgen Moltmann explored the concept of a relational understanding of the Trinity. Perichoresis, he explains, allows the three Persons of the Trinity to be individual yet find their fullest expression through their interdependent relationship.[26] John Zizioulas argues that this is a model for all relationships, in that through our communion with each other we affirm our identity. We are not individuals who coexist, but rather persons who mutually exist.[27]

Zizioulas's argument requires fluidity in relationships, rather than an emphasis on particularity. As Volf rightly points out, without the aim of ultimate fluidity there will always be a closed boundary between individuals.[28] Such closed boundaries give rise to the risk that we revert back to the type of personhood defined by Singer, the particularity of functionality. In the case of dementia, dementia itself can be the boundary for both the diagnosed and those around them, since the presenting effects of the disease define the diagnosed and their relationships. This could create what Kevern calls a 'dementing society' in which there is more harm than good.[29] It seems that a natural counterbalance to the dementing society is to advocate for fluidity of relationships to enable the creative opportunities of relationships with the dementia-diagnosed.

A consideration of the perichoresis of the Godhead also encourages us to give reasons why we should hold the dementia-diagnosed in relationship. First, Walter Brueggemann argues that God and Adam will always be in relation because God breathed life into Adam.[30] This means that Adam, and hence humanity, will always be in relationship with God.[31] Second, Zizioulas and Swinton both offer christological arguments to move the imperative for personhood found in relationship beyond being focused exclusively on the Trinity. For Zizioulas, it is not simply that humanity replicates divinity, but rather that Christ embodies all who are 'in him' within the Trinity.[32] For Methodists this should not be an unfamiliar idea since we talk of sanctification as becoming fully formed in the image of Christ. This is emphasised by Swinton who uses Bonhoeffer's Christology of Christ 'being-for-us' to argue that when Christ is for us, whether we recognise it or not, then we have an equality before God. Therefore, if Christ is for me and Edward, then I must be for Edward too. So it is through Christ that our mutuality in communion with each other and with the Trinity exists.

Having understood our personhood to be defined by the relationships in which we are bound through Christ to be part of the perichoresis of the Trinity, the next important question is how this theological argument helps to form a response to the situation and begins to find the voice of hope.

Theology and situational analysis in dialogue

The theological argument I have sketched so far contrasts the espoused and operant theologies of the Church. The question is whether these theological ideas will stand up to the scrutiny of the situational experience. The situational analysis suggests that the dementia-diagnosed becomes a stranger and appears less of a person. In many ways, the situational experience voices Singer's conclusion of the impact of dementia on personhood. Is Edward less of a person if he no longer functions like the person he is sitting next to or in the way he used to? When I looked at my own mother, did I see a person whom

I still affirmed through my relationship or did I see a non-person? Surely my answer must be that I see a person, because I am still in relationship with her, and nothing can diminish that. This view is upheld by writers such as Bryden and Maureen Russell. Russell has written of her relationship as carer for her great-aunt through the lens of feminist theology. She concludes that resisting her great-aunt's power in their relationship would mean that their relationship becomes asymmetric. This would deny her great-aunt a vital role of mutuality[33] in which she and Maureen could continue to discover their own personhood. Maureen's great-aunt reveals to Maureen something of Maureen's personhood that reminds her of her humanity and delivers Maureen from the delusional functional understanding of herself. In other words, it allows Maureen to see herself. This is what Wannenwetsch calls the angelic mission of the disabled.[34]

To recognise the angelic mission of the disabled means that we are forced to listen for their voices and to recognise the gifts that the dementia-diagnosed bring. John Hull, the Christian theologian who explored the deep impact of blindness through his own experience, recognises his blindness not so much as a defect but as a gift of a different capacity.[35] In the same way, through our relationships with the dementia-diagnosed, we need to recognise the gifts they offer to the community – different as they may be.

The dialogical contrast between situational and theological analysis led me to conclude that there is sufficient scope to explore a new theological response to the life of the dementia-diagnosed within the life of the Church. I will now go on to explore the actions that will facilitate the further exploration of this theme.

A suggested response

The crucial response to our dementia-diagnosed friends is a commitment to a longer-term sustained engagement, which I have so far argued should be one of deepening relationships with the dementia-diagnosed. In its purest and most fluid embodiment, this must be permissive of engagement in the entire life of the church. Underpinning this engagement is the observation that in the Genesis narrative God *presents* Eve to Adam.[36] This, Wannenwetsch argues, reminds us that forming relationships will not happen instinctively.[37] If they did, then our operant theology and praxis might already be inherently different. Therefore, we must focus on actions that are designed to facilitate encounters in which personhood can be formed through relationship.

The first action, which we have already begun in our context, is to engage key members of the congregation in theological discussions about personhood and about the place of members like Edward. This has begun to expose the church to a different, possible 'normative'[38] theology, recognising the angelic mission of the dementia-diagnosed. However, there are still further issues and ideas that need to be discussed and challenged.

Second, the church must move beyond the idea that 'success' in our relationships is measured by certain signs of recognition and participation. This approach will create and sustain asymmetric relationships and deny the positive impact that the dementia-diagnosed have on us. Further, the opportunity for mutual growth in relationship relies on equality and openness for all parties to be influenced by the other. We need to take seriously their confusion and ask why we never thought of it like that. We need to take seriously and celebrate what they celebrate; we must listen to their stories and tell them ours. We must learn to see faith as they see it, often stripped bare of our pretensions and masks, because it will deepen our faith rather than threaten it.

Practically, of course, many feel ill-equipped to deal with members like Edward, which often leads to the care of the dementia-diagnosed within the church becoming a privatised concern in separate groups run by specially trained people. This approach naturally creates a carer–cared-for relationship to a greater extent than the expected pastoral care relationships within the church community, and inhibits the expression of the gifts that Edward and others like him can bring to the church. Therefore, Edward's full participation in the whole life of the church, as would be possible to the non-dementia-diagnosed, needs to be facilitated in a less threatening way. The creation of a small group to pay particular attention to Edward at church would alleviate some of the fears. The group would ensure that Edward is safe and others are safe around him by being trained to manage Edward and the presenting features of his dementia.

Fourth, there is the possibility of extending this to the inclusion of members who are housebound or in residential care. This population find it difficult, if not impossible, to attend church regularly. So how might this approach engage with them? It is important to recognise that no action we take as a church will ever be perfect and we have to live within the constraints of physical ability. However, this does not mean that such members are forgotten within the church community. The idea of a 'visiting team' could be considered in our context where relationships can be continued over time. Other ways of remembering the housebound before the congregation are being explored: for example, naming them in the prayers and specifically extending Holy Communion to them, to enable us to grow in faith together.

Finally, it is to be noted that implementing these actions will not birth a perfect community or reflect a perfectly formed theology. Instead, we need to continually observe, reflect and act, remembering that Lartey's Theological Form is not a linear process but will demand that these actions form the basis of the next iteration of action and reflection.[39]

Conclusion

I have argued that there is a different narrative that these local churches, and many other churches like it, could inhabit in order to enable the dementia-diagnosed to be recognised as something more than their diagnosis. I have argued for an alternative theological paradigm of personhood based on the perichoretic model of the Trinity, viewed through the lens of the Genesis 2 creation narratives in which we are bound together through our common creation in the divine image and by our relationship with Christ. This approach enables all who are differently abled to be acknowledged as angelic missionaries to the community. Whether or not the church will have the intent to live together differently as a community and design ways to allow these pastoral encounters to happen is yet to be seen.

Notes

1. T. Kitwood, 'The Dialectics of Dementia: With Particular Reference to Alzheimer's Disease', *Ageing and Society* 10 (1990), pp. 177–196, and in Swinton 2012, pp. 39–41.
2. Lartey 2000, p. 132. The 'pastoral-cycle' developed by Emmanuel Lartey has a strong emphasis on the situation which forms the genesis of observation and response. It takes a 'multi-perspectival' approach, considering both the situation and theology in a dialogical tension to tease out possible responses. Intentionally circular and iterative, the model allows a perpetual reconsideration of the experience as each response creates new experiences for reflection. The model begins with an experience which is then analysed in the 'situational analysis' of stage 2, which seeks insights from other perspectives. Stage 3 considers the theology that could form a response, and this is then held in dialogue with the situational analysis in stage 4, before a potential response is formed.
3. Moltmann 1981, p. 174.

4. Wannenwetsch 2007, p. 188.
5. Wannenwetsch 2007, p. 192.
6. Frank 2000, p. 82.
7. Moschella 2008, p. 4.
8. Moschella 2008, p. 32.
9. The names of individuals have been changed to protect their anonymity.
10. Cameron 2012, p. 13.
11. Stuckey 1995, p. 75.
12. Goldsmith 2008, p. 120.
13. Bryden 2005, p. 152.
14. See: http://www.livability.org.uk/church/dementia-friendly-churches/ (accessed 23 September 2014).
15. MHA 2011a and MHA 2011b.
16. Goodhall 2013, p. 174.
17. World Health Organization 1993.
18. Swinton 2012, pp. 39–41.
19. Kevern 2010, p. 174.
20. Spaemann 2006, p. 257.
21. P. Singer, *Practical Ethics*, 2nd edn, Cambridge: Cambridge University Press, 1993, p. 86, cited in Swinton 2008, p. 25.
22. See Psalm 139:13–14 (NRSV).
23. Wannenwetsch 2007, p. 188.
24. P. Trible, 'Depatriarchalizing', *Biblical Religion* 41(1) (1973), pp. 30–48, p. 34.
25. Kitwood 1997, p. 8.
26. Moltmann 1981, p. 174.
27. Zizioulas 2004, p. 106.
28. Volf 1998, p. 411.
29. Kevern 2010, p. 178.
30. Genesis 2:7.
31. Brueggemann 2009, p. 60.
32. Zizioulas 2004, p. 106.
33. Russell 2001, p. 18.
34. Wannenwetsch 2007, p. 192.
35. Hull 2013, p. 181.
36. Genesis 2:22.
37. Wannenwetsch 2007, p. 188.
38. Cameron 2012, p. 13.
39. Lartey 2000, p. 132.

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