

METAPHOR AND STORY IN COGNITIVE DECLINE: REFLECTIONS ON ISRAEL'S
NARRATIVE SELF-IDENTITY IN EXILE AS MEANINGFUL IN THE CARE OF PERSONS
WITH DEMENTIA

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INTRODUCTION

Although compelling, Peter Kevern's suggestion that Jesus can be "spoken of being 'present to' those with dementia" (Kevern, 2009) because of the possibility that he too suffered dementia upon the Cross is speculative and unnecessary for finding resonance between faith and the troubling effects of cognitive decline. While this suggestion presents the comforting opinion that God Himself has shared in our unique sufferings, it is problematic in at least the assumption that Jesus must have experienced a condition for it to be redeemed. Furthermore, although the *pathos* of God is an essential consolation, it does not readily present itself with resources to address the complex problem of dementia. The metaphor of exile and the use of narrative, instead, present superior resources in caring for dementia. Just as narrative reconstruction was beneficial for the Israelites in exile to confront the devastating challenge of understanding their identity as God's chosen people, so too can a renewed narrative participate in the redemptive experience of families and patients dealing with dementia.

IDENTITY LOSS: DEMENTIA AS EXILE

To be in exile is to lack stable location and ability to orient; to feel an uncertainty of self that before was so evident. Meanings and values that once were unassailable now suffer, and history becomes opaque. For the Israelites relocated to Babylon following the destruction of Jerusalem in the 6th Century BC, the certainty of being the people of God and possessing the

Chosen Land promised to the Patriarchs was jeopardized, and the future was unclear. “The end of the land of course means the collapse of all public institutions and all symbolic expressions of well-being and coherence (Brueggemann, 2002, p. 108).” Brueggemann points to the nature in which Jewish identity was rooted in possession of the land, religious and social practices embedded in the culture and the security found in the continuity of community. With exile came a total destabilization of self-understanding that risked, as with virtually all conquered peoples in history, dissolving of identity within the dominant empire of the time. Without the tangible elements understood to constitute a people group, the ability to transcend this cataclysm and maintain any sense of Jewish identity was implausible.

Like exile, the systemic effect of declining cognition in dementia is far reaching, cutting at the core of conceptions of selfhood and identity. The struggle for families to make sense of identity in the presence of dementia is made even more challenging in the West, where personhood is based on highly individualistic and bounded notions of self (Cushman, 1995). Although the social construction of identity is becoming an increasingly recognized anthropology (Hayes et al. 2009), the lived experience of identity in the West still holds autonomy and self-determination as supreme values. This presents a particularly troubling picture for sufferers of dementia who, based on the decline of neuroanatomical structures critical to the continuity of biological processes involved in identity (memory, semantic meanings, orientation in space and time), “experience a crumbling away of their former self-images without simultaneous developments of equally valid new ones” (Charmaz, 1983). Furthermore, family narratives of dealing with the effects of severe cognitive impairment in their loved ones suggest *family members* may experience losses of identity and selfhood (Hayes, et al, 2009; Goldeteen, et al., 2007; Karner & Bobbit-Zeher, 2006, etc.). Dementia is particularly unsettling because of the

implications that the course of disease has for understanding the nature of human *being*, in that cognitive decline results in “abject enselfment...in which the body remains attached to an individual who no longer is a self (Waskul and van der Riet 2002, 509).” Lacking the ability to effectively develop new memories, accurately recall what has transpired, or locate oneself in space and time, complicates definitions of personhood. It is as though personhood becomes exiled from body as the body withers and dies.

RETURN TO STORY: NARRATIVE AS SOURCE AND RESTORER OF IDENTITY

Narrative has long been used as both the means of situating one's identity in the world and for making sense of the experiences encountered throughout life. Regarding Israel, the telling of its history was essential to making sense of its identity as the people of God, and remained so, despite the loss of much that is tangible about existing as a people group. Although, as Goldingay writes, “Israel is more fundamentally the people of Yhwh than it is a political, ethnic or geographical entity (Goldingay, 2006, p. 173),” physical elements were the primary markers of Yhwh's covenant people. Prior to exile, this connection of people to place and practices was retold through story to reinforce the importance of the deeper meanings inherent in the promises. After conquest, this became no less true as Israel faced its most debilitating experience of separation, disruption and loss. Rather than the incorporation of Jewish identity within the powerful culture of Babylon, the Jewish self-understanding was re-visioned. The continued participation as “people of the covenant”, despite the absence of land, Temple or cultic practices, suggests Jewish identity was developed more substantively in relationship to Yhwh than in the physical properties of being a religious nation—in this connection holds the deepest

promise. “The Lord of history gives history to the landless who should have no history. He takes the barren as mother of promise. He takes the slaves as bearers of freedom. And now he takes hopeless exiles as his new people (Brueggemann, 2002, p. 118).” Books such as Deuteronomy, Lamentations, Chronicles and portions of Jeremiah, Ezekiel and Isaiah, became narrative means to re-interpret the past to incorporate the present with the greatest hope for the future (Freedman, 1973). The “hopeful imagination” of the people allowed for the reconstitution of core narratives into new stories to transcend the loss and transform despair (Brueggeman, 1986).

Concerning dementia, the metaphor of exile is useful for considering the despair of lost ability, the anxiety of uncertainty, and lament at diminished capacity. Similarly, the suffering of dementia presents the opportunity to discover new narrative possibilities for understanding identity, and hope for renewal. Within the limited anthropological framework of persons in the West as bounded, autonomous selves, cognitive decline means the waning of personhood. Members of the family perceive that their loved one is “no longer themselves”, suggesting that human identity is understood primarily as a function of neuroanatomical structures. However, identity loss in *caregivers* when care-receivers do not remember them belies the alternate reality of the mutuality of personhood – it is experienced as a loss of self-identity (Hinton & Levkoff, 1999). Furthermore, loss of cherished roles—as “daughter” or “husband”, and replaced with roles such as “caregiver”—points to the complexity of loss and dislocation that occurs when confronting dementia (Karner & Bobbitt-Zeher, 2006). The complicated impact upon families suggests persons are better understood as embodied in the rich narrative tapestry of family and community, and not simply embedded in brain structures. As such, care for the demented family member *is* care for the self that resides in the memory and identity of the patient. Continued telling of family stories, richly encircling the demented person in the narrative history that has

shaped and molded them throughout their life, preserves the continuity of self and the family as a whole (Adams, 2000). Furthermore, conscientiously maintaining the natural roles of relationship that preceded the loved-one's decline in functioning, in conjunction with newly acquired responsibilities for caretaking, continues to tell the story of identity through family ties and love (Karner & Bobbitt-Zehrer, 2006).

RESTORATION: RETURN FROM EXILE AND AN ESCHATOLOGY OF DEMENTIA

“The Old Testament stories of exile might be a resource, perhaps the only resource, to move us from denial and despair to possibility. Ancient Israel understood that unless loss is examined and understood, newness will not come (Brueggemann, 1997, p. 631).” In order to move into a place of greater vision, understanding, and promise, Israel had to face the reality that homelessness and exile was their new story, and that this homelessness was directly tied to deep relationship with Yhwh (Brueggemann, 2002). Although the land would once again return into the hands of the Israelites, they remained an occupied people without unequivocal possession. Their temporal fate remained in the hands of their conquerors, but their narrative imagination in captivity helped them break out of the more limited vision of restoration to see a broader picture of God's covenant promise. Through a new understanding and vision of the original promises, the despair, loss and grief were converted to hope for restoration and ultimate renewal. Return to the land, however, was not the end of the story, as strife, occupation, genocide, and many other heartaches, sufferings and troubles would await. The reality that faces us all, despite experiences of homecoming that restore and renew us, is that the ultimate restoration is yet to come. Though a momentary joy was provided in the brief return, the fleeting reality of homecoming points

instead to the final consummation of all things, to which the renewed vision of Israel's hope and narrative would point (Jones, 2001).

Given the storied nature of persons, the heartache, loss, despair, and grief at the diminished capacity of the person with dementia is ripe for the powerful authorship of new narratives. Families must reconcile the decreasing functional ability of the person with dementia; however, when the demented family member is perceived as becoming less and less human because of an overly anatomical understanding of human identity, then they are likely to be perceived as a greater and greater burden. Families that understand the embedded nature of human inter-relationship, recognize that in maintaining the integrity and continuity of their loved one through story, relationship and caregiving, they are also maintaining something critical to their own experience of self. And yet, the reality of ultimate loss is ever present as the course of disease will inexorably lead to death. The family must take up where the functional ability of the person with dementia leaves off; but instead of viewing this as a burden of care for a body that lacks an identity, caregiving functions as a continuation of the loved one's identity. Just as the Israelite re-visioning lead to a renewed hopefulness for ultimate restoration, so too does the family exist as an eschatological hope in the restoration of the patient with dementia. By maintaining the story of the person, by preserving the continuity of relationship and by embodying the functional abilities of the family member that are in decline through caregiving, the family proclaims the on-going identity and selfhood of the person suffering with dementia that will transcend both the disease and death.

CONCLUSION

Conventionally, neither dementia nor exile are conceived of as a message of hope. However, within the economy of God's salvation history, exile functions not as a destroyer of hope, but of a critical declaration of where hope ultimately resides. Through the use of narrative, the Israelites came to the conclusion of God's purpose in the broader restoration of all things that transcended the elements of what Israel thought it required to be the people of God. Similarly, for people suffering with dementia, this disease has the potential to point to a greater eschatological vision through the renewed understanding of human identity and family narrative. By maintaining the continuity of personhood for the loved one with failing cognition, the family, together with the patient, points to the enduring nature of human identity until it receives its final homecoming: complete renewal in the glorified community of faith.

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