

CAIS Paper: Drawing Clocks without Time: Alzheimer's, Marginalization, and the Liberatory Potential of Object Memoir

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Abstract: Dementia and Alzheimer's disease know no boundaries. While this much is known, there is little beyond the medicalization of onset to provide insights into individuals instantly marginalized by a diagnosis with no future. How can surrogates and object memoir be mobilized to empower the voices of the cognitively disabled?

Resumé:

1. Introduction

Imagine that you are living your life, in good health, pursuing your daily routine, but troubled by a vague sense that something is just not quite "right". Perhaps you found yourself turning a corner on your regular walk to the grocery store, having a momentary anxiety that usual landmarks were unfamiliar. Were you lost? Misdirected? Caught up in the kind of distracted thinking that can catch us wondering when we last checked the rear view mirror? One of your children recently chided you for missing an important detail in a family story. "Don't you remember when?" Leslie asked, and you were not sure that you actually did remember that particular "when". The familiar narrative that has been the trademark of years of holiday meals together seems somehow more fragmented, and your timing and delivery less sure. Then "something" happens to prompt a referral to a professional with an interest in your cognitive functioning. House keys put in the freezer and forgotten? A conversation with a group of nuns in your bedroom, which, to all but you, seemed real enough at the time? The cognitive professional asks many questions then invites you to draw the face of a clock. How silly, you think to yourself, while obliging with a jumble of numbers clustered in the bottom right hand quadrant of a vaguely rounded shape. "Is this what you wanted?" you inquire politely. And in an instant your life transforms to one with "no future" (Edelman 2004).

With a label of "mild dementia", or "early-stage Alzheimer's Disease (AD)", you enter the territory of the medicalized, the disabled, the one with a "disease", joining the ranks of the variously marginalized. As Cooley (2011) has observed, "To this litany of some of the most marginalized members of society's now, many of whom are figured as having tenuous or non-existent relations to the future, we might add cognitively disabled adults." Your life story now ceases to have a credible narrator – at least in the eyes of those secure in their cognitive "normalcy".

2. Life story and disability

G. Thomas Couser (2011) has suggested that, "life writing is all around us; we live and breathe it." Lives can be written in multiple ways; his taxonomy reflects the enormous growth over the past two decades in what he refers to as the "memoir boom". Categories include the

“somebody” and “nobody” memoirs of the famous and unknown, respectively (Adams 2004). To these Adams (2004) adds the three categories of (1) childhood memoir (“abusive, alcoholic, impoverished, minority”, etc.), (2) physical catastrophe (“violence, quadriplegia, amputation, disease, death”), and (3) mental catastrophe (“madness, addiction, alcoholism, anorexia, brain damage”). Couser (2011) suggests that the rise in (predominantly nobody) memoirs around the latter two categories has corresponded with – perhaps even fostered or promoted – a corresponding flourishing of disability life writing, noting that, “Disability has been a staple of cultural production for centuries, indeed millennia, but only in the recent past has it generated such a large body of self-representation in the form of personal testimony.” Davis (2006, 3) reminds us that, “Life writing (life narrative, autoethnography, autobiography) emerged alongside the disability rights movement as a counternarrative to medicalized discourses that position the disabled body outside the boundaries of normalcy.” Couser (2006, 401) adds further that, “It provides people with disabilities the power to occupy the subject position in the face of decades of misrepresentation”.

Life writing as Davis (2006) and Couser (2006) describe it may offer a practical means for enabling the “voice” of the marginalized. These are what Cornell (1994) refers to as “the Other” – the individuals who exist outside of an exclusionary system maintained by “the One”. And while life narrative, autoethnography, and autobiography may empower the disenfranchised to somehow permeate the hegemony of normative ways of existing and acting in the world, they (as life writing) are liberatory strategies denied to those of dubious voice, or with a voice that has no “expectation of being heard, understood, taken seriously” (Code 1995, ix-x). Such is the discounted voice of dementia or Alzheimer’s Disease – the voice with “no future”.

3. Information Science and Surrogates: theorizing a voice for “the Other”?

As Bowker and Star (1999), among others have confirmed, information science as a discipline has demonstrated through its tools and techniques an alignment, even a complicity with the normative. Categorization and classification have tended, either to reflect dominant modes of thinking about the world, or to reinforce the reproduction of life as it is, and not as it might or should be re-imagined (Mai 2004). Constructivist approaches to rethinking how, why, and in what context we name, label, and sort are challenging fixity in favour of greater permeability. Nonetheless, the surrogates we still design to represent or serve as a substitute for a person, place, event, or thing (a name, a label, etc.) remain largely rule-bound, prescriptive, and amenable to uniformity and consistency of application.

In a spirit of further challenging current perspectives regarding the nature and role of the surrogate, an exploratory collaboration was undertaken (Howarth and Olson 2013). How could the representative substitutes that information science has developed within a regularized framework of consistency and fixity be moved into the realm of the permeable and the liberatory? The research question asked, specifically: Can the surrogate discover or construct space for the narratives of marginalized voices?

First steps were described with reference to a study, completed earlier, of individuals with mild Alzheimer's Disease (AD) (Howarth and Hendry 2011). Findings suggested that objects standing in as surrogates for an event, a person, or a period of time were evocative in the recall

of memories, often expressed as detailed and vivid stories. Moreover, the one-on-one sessions during which the surrogates were considered and discussed offered a kind of "neutral space" in which to engage in a safe, nonjudgmental, and social retelling of personal narratives. The objects, in essence, gave "voice" to individuals who are often marginalized or isolated in their daily lives.

While at least a tentative answer to the research question was reported (Olson and Howarth 2013), further explorations towards theoretical framing have continued apace. More recently, the idea of "object memoir" has been considered as a means of empowering those experiencing a loss of ability relative to life writing and associated approaches to personal memoir. This paper seeks to forge a connection between emerging studies of disability life writing as moving the marginalized beyond the discourses of medicalization, to the liberatory potential of object memoir as a strategy for telling (life) stories, and for empowering those whose cognitive disabilities have relegated them to a category of "no future". The conference presentation will offer examples of the strategy, illustrating how surrogates can be rethought to transcend fixity, restoring the credibility of a narrator whose boundaries become timeless and unlimited.

Why is this of relevance, even importance to Information Science? It is our tools and approaches that have contributed to normalizing world views – to constructing (if not always creating) naming devices, labels, categories, and logical ways of sorting and finding supportive of the normative. To the extent that we can imaginatively rethink our ways of representing, of substituting, of designing surrogates for persons, places, events, and things, we may contribute to innovative, perhaps groundbreaking approaches to conjoining "the One" with "the Other".

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