D. Grant Campbell
University of Western Ontario, London, Ontario, Canada

Nicole Dalmer
Trent University, Peterborough, Ontario, Canada

Jason Andrews
University of Western Ontario, London, Ontario, Canada

Testimonies of Communication in Dementia Care (Paper)

Abstract or Résumé:

This paper presents a study of recorded conversations, qualitative interviews, and published memoirs to articulate the role of professional information services in answering the needs of persons caring for family members living with dementia. The data from these sources reveals evidence of working naïve classifications based on images of ritual, paradox, contrast, synchrony and stability. The findings suggest that information services need to align with caregivers' working classifications, and that information, when appropriately delivered, plays a significant role in re-establishing temporary periods of stability in the caregiving relationship.

1. Introduction

In this paper, we use a combination of evidence from recorded conversations, qualitative interviews, and published memoirs to articulate the role of professional information services in answering the needs of persons caring for family members living with dementia. The push to use information to be prepared for or to meet the complex medical and social needs of a growing older adult population is tempered by family caregivers' continued reports of feeling inadequately prepared, informed, and supported (Bookman & Harrington, 2007). More than 80% of family caregivers desire more information on caregiving topics (AARP & NAC, 2015), with their "high levels of unmet informational needs" (Morris & Thomas, 2002, p. 186) persisting despite increasing availability of information in online and print formats. While accessibility and quality of information are two desired characteristics in choosing information sources (Harland & Bath, 2008), ongoing evidence that caregivers encounter difficulties when seeking and using information about or for the older adult in their care (Allen, Cain, & Meyer, 2018; Washington, Meadows, Elliott, & Koopman, 2011) suggests a different approach to supporting caregivers' information needs.

2. Background

Individuals caring for family members with dementia experience a complex network of information needs. Dementia continues to be difficult to diagnose with any specificity, and the different kinds of dementia, such as Alzheimer's disease, Lewy body dementia and vascular dementia, have different causes, symptoms, and trajectories (Alzheimer Society of Canada, 2016). Furthermore, lay persons caring for family members, particularly in home environments, must negotiate a wide range of knowledge domains, many of which may have been unfamiliar beforehand: household finances, hospital procedures, basic nursing tasks, housekeeping, medicine, and the bureaucracies of local health and home care systems (Wong, Gilmour, & Ramage-Morin, 2016). In particular, the caregiver must reconcile different objectives of knowledge. Medical and social research seek to address broader questions: how dementia is caused, how it can be prevented and how it can be cured, and how the broad network of supports in society can adapt to growing numbers of individuals living with dementia. For the individual living with dementia, concerns of causes and cures may be less pressing than concerns about the quality of life in the time remaining (Campbell, 2011). For the family caregiver, the challenges of dementia call less for solutions than for endurance. The caregiver's aim shifts from mastery to one of simple survival; caregivers struggle, not just to preserve their individual health, but also to preserve a long-standing relationship with the care recipient, when the challenges of dementia threaten to taint whatever time is left.

In caring for family members with dementia, caregivers frequently encounter challenges of communication. Individuals with dementia frequently suffer from progressive aphasia which robs them of vocabulary (National Institute on Aging, 2017). Even without this disability, dementia impairs the individual's ability to follow the normal implicatures of conversation, such as respecting length, limits on information, and veracity (Grice, 1989). These challenges make it difficult for caregivers and their loved ones to understand each other, giving an added level of complexity and bewilderment to the problems of care.

Dalmer (2018) spoke with thirteen family caregivers of older adults living with dementia about their care-related information work. When asked if they had ever considered the public library as a source for information, none of the thirteen caregivers had. Evidence from other studies indicates that caregivers frequently bypass important information hubs such as libraries when seeking support and information. This suggests that knowledge organization systems used by information providers needs to adapt more specifically to the rhythms and eccentricities of caregivers' information needs. This paper, therefore, explores an important question:

How can we organize information on dementia and caregiving in a way that best supports the experience of caregivers trying to adapt to these communication challenges?

3. Method:

This paper draws from cognitive science and knowledge organization theory to address the research question. "Theory" theory in cognitive science posits that individuals form naïve classifications that enable them to function within the world before they acquire the more formal classifications that prevail in their social environments (Rogers & McClelland, 2004). Knowledge organization theory offers a pattern of interaction between naïve and formal classifications, in which the naïve classifications formed within specific knowledge domains accumulate credibility until they are absorbed into revisions of formal classifications (Beghtol, 2003).

In this study, we triangulate data from three different sources in an attempt to discern the traces of naïve classification that family caregivers adopt when facing the continuing challenges. Through a series of exploratory interviews with personal caregivers, we sought accounts of how they deal with challenges in communicating with their family members. Through a set of videos acquired through YouTube, we examined the testimony of individuals living with dementia, together with conversations between individuals with dementia and their family caregivers. And through three published memoirs—*Enter Mourning* by Heather Menzies (2009), *The Long Hello* by Cathie Borrie (2015), and *Be With* by Mike Barnes (2018)—we examined the more elaborate and considered reflections of individuals who have experienced the caregiving process at close quarters for a long period. We used the insights from these sources to intuit how professional information providers such as libraries and dementia-related community services could adapt their information provision to caregivers' needs.

4. Results:

The preliminary results from our study indicate the following patterns that directly impact their engagement with information:

4.1 Before and After: Caregivers' information needs tended to change dramatically after the loved one passed away. Before the death, information needs tended to be satisficing and highly localized: how to master a particular, pressing challenge. After the death, the pattern shifted to one of reflective synthesis. Libraries appeared to offer greater support to this retrospective synthesis than to the immediate and pressing concerns that dominated while the person with dementia was alive.

4.2. Ritual: Caregivers spoke of the importance of regular, repeated activities, often centering around some principle of sanctity or heightened significance, outside the rhythms of everyday life. The appreciation of such activities—the ritual of making tea, sitting by the window looking at the birds—tended to make the caregivers more attuned to patterns of rhythm and repetition in their broader lives, through such activities as dancing.

4.3. Paradox: Caregivers' accounts betrayed the presence of a constant paradox of presence and absence. On the one hand, they spoke of the person "disappearing" as the disease progressed, becoming more and more a stranger as access to memories of their shared life became more tenuous. On the other hand, they frequently insisted that the person was "still there." They made frequent use of an inside-outside metaphor, referring frequently to the person's tendency to go "inside" to a private place where the caregiver could not follow.

4.4. Synchrony vs. Diachrony: Interaction between caregiver and care recipient appears, at times, to exist solely in the moment: the person with dementia showed little awareness of the other person's identity, and little interest in the past. At such times, the person with dementia appeared not to recognize the caregiver, beyond a basic awareness of a bond. At other times, the interaction carries multiple overtones from the past, in which the person with dementia appeared to be conflating the present moment with memories, and conflating the caregiver's identity with those of figures in the past.

4.5. Stable anchors: successful interaction appears to take place at times when the caregiver and the loved one are in a state of synchronization, a synchronization made possible by both actors feeling safe and secure in the moment. For this reason, repeated, ritualistic activities seem to be most successful, perhaps because the repetition reduces uncertainty, perhaps because many of these rituals take place in relative quiet, placing less cognitive demand on the person with dementia, and perhaps also because the slower pace of the ritual helps the caregiver to be calm and to project calm.

5. Conclusion

The findings of the study suggest that communicating meaningfully with a person with dementia follows a repeating pattern of disruption caused by cognitive decline, followed by an adaptation leading to a temporary stability, in which the caregiver can successfully interpret the cryptic interchanges, and both parties can establish a temporary state of stability and trust. However, the abrupt changes that take place with dementia make such stability transient; every fresh decline in the care recipient's cognition creates the need for fresh negotiation and interpretation. While libraries are particularly adept at providing access to materials that support a retrospective analysis and synthesis of the experience once it is over, they are less well-adapted to supporting such unpredictable and frequent changes. To support caregivers, professional information providers need to adopt strategies that support "tweaking": providing caregivers what they need to adjust the environment into a fresh, though transitory, state of stability.

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