

2018

Communicating with Library Patrons and People with Dementia: Tracing an Ethic of Care in Professional Communication Guidelines

Nicole K. Dalmer

The University of Western Ontario, ndalmer@uwo.ca

D Grant Campbell

The University of Western Ontario, gcampbel@uwo.ca

Follow this and additional works at: <https://ir.lib.uwo.ca/fimspub>

 Part of the [Library and Information Science Commons](#)

Citation of this paper:

Dalmer, Nicole K. and Campbell, D Grant, "Communicating with Library Patrons and People with Dementia: Tracing an Ethic of Care in Professional Communication Guidelines" (2018). *FIMS Publications*. 247.

<https://ir.lib.uwo.ca/fimspub/247>

Communicating with library patrons and people with dementia: Tracing an ethic of care in professional communication guidelines

Dementia
0(0) 1–16

© The Author(s) 2018

Reprints and permissions:
sagepub.co.uk/journalsPermissions.nav

DOI: 10.1177/1471301218790852

journals.sagepub.com/home/dem



Nicole K Dalmer  and DG Campbell

The University of Western Ontario, Canada

Abstract

In both library reference work and dementia care, communication between personnel and service recipients can be both complex and complicated. Professionals in both fields have therefore developed protocols and standards to assist personnel in handling these interactions. In this article we detail an exploratory comparative study that used an ethic of care framework to compare prominent guidelines for reference librarians (American Library Association's Reference and User Services Association's *Guidelines for behavioral performance of reference and information service providers*) with guidelines for workers in long-term dementia care settings (the National Institute for Health and Care Excellence's *Guideline on supporting people with dementia and their carers in health and social care*). We explored how both sets of guidelines frame the act of communication as a combination of regulated procedure and empathetic discourse to determine how the similarities among and differences between these two guidelines provide useful insights into each other. **[AQ1]** Our examination was structured using an ethic of care lens, which emphasizes the importance of interpersonal relationships, reciprocity, and empathetic benevolence. **[AQ2]** Using specific phrases in each set of guidelines that align with and are evidence of Tronto's (1993a) four moral principles of care, we ultimately discovered, in both sets of Guidelines, an underlying ethic of care: a repeated insistence upon embedding procedures within behaviour that manifests attentiveness, responsibility, responsiveness, and competence.

Corresponding author:

Nicole K Dalmer, Library and Information Science, The Faculty of Information and Media Studies, The University of Western Ontario, FIMS & Nursing Building, Room 4083, London, Ontario N6A 5B9, Canada.

Email: ndalmer@uwo.ca

Keywords

ethic of care, Library and Information Science, reference work, care work, communication, professional guidelines

Introduction

This paper arose from an intuition: that the problems and questions pervading dementia care have echoes and resonance with the problems and questions that pervade the provision of information services. In January 2017, an individual with Alzheimer's disease (AD) posted a message to alz.org, describing her tendency to become hostile and aggressive:

My guess would be aggression and hostility are from our cognitive capacity being overwhelmed. . . . Most "bad behaviour" is misunderstood frustration, pressure from within our own selves or other people pressuring us to perform. I kept trying to keep up and BOOM. (alz+, 2017)

More than 15 years earlier, information researcher Carol Kuhlthau (1991) articulated the various affective states that accompany different stages of the Information Search Process. The exploration stage, she argued, is characterized by feelings of confusion, frustration, and doubt: 'Users may find the situation quite discouraging and threatening, causing a sense of personal inadequacy as well as frustration with the system' (p. 367).

These affective states are too similar to ignore. Clearly, certain stages of the information search process arouse feelings – and responses to those feelings – that begin to resemble the challenges of living with dementia. Furthermore, both dementia care workers and information professionals work within a growing awareness that providing assistance in both contexts requires care and respect on many fronts: physical, social, emotional, and psychological. Truly successful mediation, in both contexts, requires acknowledgement of the individual as well as the requirements and limitations of the system within which both the caregiver and individual operate. This requirement has been elaborated by Gilligan, Tronto, and others as an ethic of care: an approach to caregiving that emphasizes human relationships, manifested through the intertwined qualities of attentiveness, responsiveness, responsibility, and competence.

If the problems are similar, so might be the mediating strategies of professionals who seek to provide help: strategies of detection and intervention that evolve through prolonged experience, trial and error, and pooling of insights and suggestions within a community. For example, according to Harmeier's (2016) anecdotal account of providing reference through online chat, 'occasionally, chat librarians need to play the role of crossword puzzle takers, intuitively filling in missing pieces and doing a bit of detective work and outright mindreading' (p. 260). Similarly, Wexler (2004) describes the investigative work long-term care staff do to unearth and track dementia residents' unique and varied interests, skills, and passions, including, for example, specific hygiene habits and morning meal preferences.

In both reference work and dementia care, communication is complicated, and interactions can often become frustrating for both parties, sometimes degenerating into hostility. Professionals in both fields, therefore, have developed protocols and standards to assist personnel in handling these interactions. To what extent are different protocols addressing

similar interactions? And to what extent do the practices of librarianship offer skills and insights for those working with individuals living with dementia? Likewise, to what extent can Library and Information Science (LIS) professionals and researchers learn from the insights of those working with individuals living with dementia?

We argue that understanding and exploring the communication of information to those living with dementia is best approached through an ethic of care, which offers a lens that emphasizes the importance of interpersonal relationships, reciprocity, and empathetic benevolence. From this perspective, LIS has a rich heritage and tradition of providing empathetic and helpful communication in complex and cognitively demanding situations. As information scholars have long observed and studied, information professionals confront a range of emotional responses to the information search process (Kuhlthau, 1988, 1991, 1993, Mellon, 1986), many of which – responses of despondency, anxiety, confusion, and avoidance, if not outright hostility – resemble responses encountered by staff in dementia care. In this paper, we report on an exploratory comparative study that uses an ethic of care framework to compare prominent guidelines for reference librarians with guidelines for workers in long-term dementia care settings. We isolate specific phrases in each set of guidelines that align with and are evidence of the four elements defined by the ethic of care: attentiveness, responsiveness, responsibility, and competence. In so doing, we explore how both sets of guidelines frame the act of communication as a combination of regulated procedure and empathetic discourse. In so doing, we seek to answer the following questions:

- To what extent do guidelines for reference librarians and caregivers in dementia settings reflect an ethic of care?
- How do the similarities among and differences between these two guidelines provide useful insights into each other?

Background

Population ageing

While the ageing of the world's population is hardly news, its implications are becoming increasingly difficult to ignore. Global population ageing has been characterized as 'unprecedented, pervasive, profound, and enduring' (United Nations, 2009). The World Health Organization (2015) estimates the number of people aged 60 years or older will rise from 900 million to two billion between 2015 and 2050. This ageing trend is expected to accelerate throughout the country as an increasing number of baby boomers (often (problematically) referred to as the silver tsunami) enter their older adult years. Given its size, this cohort will increasingly highlight the complexities surrounding an ageing population and will catalyse the development of 'unique policies and practices before this generation moves into their 70s and 80s' (McPherson & Wister, 2008, p. 33). With these trends in mind, we can go further and speculate that the challenges facing care providers for this ageing cohort will be equally complex. As researchers in health information science, we anticipate that caring for this large and unwieldy population of older Canadians will call for unprecedented pooling of expertise from a variety of fields, including librarianship.

Understanding dementia

Increases in older adult populations are also marked by increases in age-related health conditions, including that group of neurodegenerative diseases caused by varying chemical and pathological changes in the brain that we label as dementia. The different patterns of brain damage result in different types of dementias, and consequently, in different symptom presentations (Harland, Bath, Wainwright, & Seymour, 2017). AD, the most common cause of dementia (Wackerbarth & Johnson, 2002), is marked by losses and changes in memory, mood, thinking, problem solving and reasoning, communication, and behaviours, as cognitive abilities progressively deteriorate (Alzheimer Society of Canada, 2010). Individuals living with dementia experience progressive deterioration in cognition and behavioural functioning and as a result have increasingly impaired abilities to contend with activities of everyday life, resulting in complex needs to be met by others. Needs to be addressed are often related to changes in behaviours associated with AD, which include screaming, repeated calling out, disturbances in sleep–wake cycles, crying, and pacing (Kitwood, 1997). As these behaviours can become increasingly difficult for care providers in both home environments and long-term care facilities, an increasingly important issue for care providers ‘is how to maintain acceptable standards of care and quality of life in dementia with limited funds and staff, inadequate training of care staff, and increasing comorbidity and dependency levels in dementia’ (Chenoweth et al., 2009, p. 317).

LIS approaches to dementia research

As Canada and other nations grapple with the growing challenges associated with dementia care, many different disciplines are discovering that their domain-specific training has relevance to this challenge. LIS is no exception. In addition to providing access to information resources, reviewing resources, and providing innovative programming (CILIP, 2014; Cochrane, Klocker, & Towers, 2014; Dankowski, 2015), information practitioners and scholars are exploring, more broadly, ways of communicating information to individuals living with dementia as their disease progresses. As individuals living with dementia may ‘end up prematurely or inappropriately in residential long-term care’ (Morton-Chang, 2015, p. ii), understanding how to better communicate with those living with dementia is of critical importance to enable their ability to live with reasonable independence in the community for as long as they desire. And if residential long-term care is unavoidable, effective communication is essential to maintaining their quality of life.

Until now, LIS is described as being peripheral to existing collaborative and interdisciplinary activities and contributions to address the challenges associated with rising incidences of AD (Erdelez, Howarth, & Gibson, 2015). The small numbers of existing dementia-related studies in LIS include: an exploration of how existing models of information behaviour might be useful in understanding the information behaviours of carers of people living with dementia (Harland and Bath, 2008), an articulation of the information–care relationship within the context of dementia care, including the relational practices in giving and receiving information (Barnes, Henwood, & Smith, 2016), a study examining the information needs of workers with early stage dementia (Pennington, 2016), and examinations of organizing strategies used by those living with dementia for information sense-making and recall (Howarth & Hendry, 2011). New technologies, including smart homes that provide prompts (Kenner, 2008) and interface and information architecture design

(Campbell, 2007), offer compelling and attractive possibilities, particularly those associated with big data and the Internet of Things. Indeed, one of the main themes to date within LIS-related dementia research is the role of technology in understanding and managing this disease, particularly in studying the design and use of web-based self-management or support programmes for caregivers and care recipients (Astell et al., 2009; Boots, de Vugt, Withagen, Kempen, & Verhey, 2016; Demers, 2016; Farrow, 2013; Rockwood, Richard, Leibman, Mucha, & Mitnitski, 2013; Rockwood, Zeng, Leibman, Mucha, & Mitnitski, 2012). Far fewer studies (Mortensen, 2007; Riedner, 2015) have taken up the ways in which practitioners and scholars in LIS can use their training and skills to interact with and support individuals living with dementia in everyday, face-to-face scenarios. The goal of this study is therefore twofold: to build momentum by taking up the call for a broader range of information science dementia research as put forth by a panel at the 2015 ASIS&T Annual meeting (Erdelez, Howarth, & Gibson, 2015) and to highlight the potential for LIS practitioners and scholars to participate in interdisciplinary dementia research.

This paper works towards this dual goal by, paradoxically, sidestepping advanced information technologies altogether. Instead, we explore the ways that the reference work that information professionals do, and in particular the communicative acts that comprise reference work, might be productively transferred to dementia care, and vice versa. Reference work in a library setting might be best described as the complex practices of ‘connecting people to resources, information services, and collections’ (Reference and User Services Association (RUSA), 2016) and includes ‘reference transactions and other activities that involve the creation, management, and assessment of information or research resources, tools, and services’ (RUSA, 2008). [AQ3] As the interface between patrons and the library, a great deal of reference work requires librarians to engage in acts of communication, including face-to-face encounters, with a host of different individuals and groups, each with a unique need or question. As articulated by Marie Radford (1993, 1998, 2006a, 2006b), who has conducted a number of studies on reference interactions, librarians provide more than content when providing a patron an answer; relational information is provided through verbal and nonverbal expressions: ‘this relational information is communicated through linguistic cues and gestures that convey approachability, rapport building, and empathy’ (Radford, 1996, p. 125). LIS reference professionals build on this ‘approachability, rapport building and empathy’ to assist patrons navigate a number of ‘information pathologies’ (Bawden & Robinson, 2009), among them information overload and library anxiety. Library anxiety, first studied by C. A. Mellon (1986), includes situation-specific, negative feelings of discomfort experienced in a library setting that have cognitive, affective, physiological, and behavioural ramifications. Kuhlthau (1988, 1991) later studied the symptoms of library anxiety which include uncertainty, apprehension, fear, tension, confusion, and intrusive worries. The similarities between the symptoms of library anxiety that reference librarians encounter and those experienced by individuals living with dementia that caregivers and healthcare professionals must navigate gave rise to this paper’s questions.

Methods

Unpacking care

Care provision, ‘the work of looking after the physical, psychological, emotional, and developmental needs of one or more other people’ (Standing, 2001, p. 17), is a complex practice.

While an intimate experience, directly related to how we care and are cared for, connected to how we define ourselves and those we are in relationship with, this particular type of work is also a societal phenomenon, related to how society, as a whole, produces itself: ‘care is fundamental to the human condition and necessary both to survival and flourishing’ (Barnes, 2012, p. 1). Care therefore demands ‘love and labour, both identity and activity, with the nature of demands being shaped by the social relations of the wider society’ (Graham, 1983, p. 14). Many definitions define the crux of caregiving as this dual nature of care: comprising both affect or concern and labour or tasks.

As this paper takes up and explores the nature of care in two separate guidelines using a framework established by an ethic of care, we draw upon Fisher and Tronto’s (1990) seminal definition of care:

a species of activity that includes everything that we do to maintain, continue, and repair our ‘world’ so that we can live it in as well as possible. That world includes our bodies, ourselves, and our environment, all of which we seek to interweave in a complex life-sustaining web. (p. 40)

Tracing an ethic of care

This study is grounded in an ethic of care approach, recognizing that people exist in and through caring relations with others (Tronto, 1993a). Gilligan, in her book *In a different voice* (1982), articulated an ethic of care in response to Lawrence Kohlberg’s psychology of moral development. Gilligan discovered that people can follow different paths to moral development, finding that some express a morally ‘different voice’ (an ethic of care) that is different from the esteemed ethic of justice in Kohlberg’s moral hierarchy (Tronto, 1993b). The ethic of care has continued to evolve, with Nel Noddings’s (1984) feminine approach to ethics and moral education, and Joan Tronto’s *Moral boundaries* (1993a), that converged care with feminist and political perspectives. More recent iterations by Tula Brannelly (2006, 2016) with Barnes and Brannelly (2008) and Barnes, Brannelly, Ward, and Ward (2015) continue to emphasize the importance and value of the application of an ethic of care and its emphasis on relationships that enables a weighing and balancing of different values and ideals in care.

An ethic of care stresses that humans are relational, interdependent beings. This ethic elevates care as a central value in and throughout our daily lives, offering an alternative to more biomedical understandings and conceptualizations of care. Furthermore, an ethic of care ‘recognizes that care requires a complicated process of judgment’ (Tronto, 2001, p. 64). Throughout our day, we navigate our way through a variety of judgements: moral, political, technical, and psychological. What an ethic of care approach affords, then, is an understanding that care is ‘neither simple nor banal’ (Tronto, 2001, p. 64) but instead necessitates know-how and judgements that require that ‘those involved understand the complexity of the process in which they are enmeshed’ (Tronto, 2001, p. 64). In taking up an ethic of care approach, we are able to ask what happens in care-based organizations (which can include libraries and dementia care facilities) when not all those engaged in a caring practice are able to understand the ‘complexity of the process in which they are enmeshed’? An ethic of care is an especially helpful lens that enables multiple disciplines (in the case of this study, LIS and dementia care) to respond, critique, engage with, and grapple with notions of care for individuals living with dementia. In doing so, it might offer a lens through which to both

revise and critique existing procedures that maintain quality of care and that simultaneously acknowledge the underlying (and often invisible) relational components of care.

Tronto's (1993a) proposed four moral principles of care that operationalize an ethic of care and make up the 'integrity of care' (p. 127) were used as a structuring device to read through and between the two guidelines. *Attentiveness* refers to the ability to recognize and grasp a person's care needs, *responsibility* referring to the acceptance to act in response to the identified needs, *competence* is seen in the outcome of the caring process. Tronto (1993a, p. 133) argues that you can be attentive to and assume responsibility for a care need, but if one fails to provide good care, it means that in the end, the need for care was not met. Finally, *responsiveness* takes into account the care receiver's perspective and response. Corresponding to each of these four moral principles, Tronto (1993a) also proposed four phases of caring that were also used to organize our reading of the guidelines:¹

- *caring about* (attentiveness): in this first phase of care, an individual or a group identifies unmet caring needs
- *caring for* (responsibility): once needs are identified, an individual or a group takes on the responsibility to ensure that these needs are met
- *caregiving* (competence): this third phase of care requires that the actual caregiving work be done both with competence and with adept skill, accessing and allocating resources and services in a timely fashion
- *care receiving* (responsiveness): once care work is done, there will be a response from the person (or group, environment, etc.) that has been care for. Observing that response and ascertaining whether it was the care was sufficient, successful or complete is crucial in this fourth phase of care.

Reading through the guidelines

The American Library Association's RUSA's *Guidelines for behavioral performance of reference and information service providers*, first published in 1996, were created to 'identify and recommend observable behavioral attributes that could be correlated with positive patron perceptions of reference librarian performance'. RUSA (2011) defines reference work as 'reference transactions and other activities that involve the creation, management, and assessment of information or research resources, tools, and services.' These Guidelines, revised in 2004 and 2011, include five key areas: visibility/approachability, interest, listening/inquiring, searching, and follow-up.

NICE, the National Institute for Health and Care Excellence, provides guidance and advice to improve health outcomes and social care in the United Kingdom. Developed by a multidisciplinary team of health and social care professionals, a person with dementia, and caregivers, the Social Care Institute for Excellence and the National Institute for Health and Clinical Excellence published a *Guideline on supporting people with dementia and their carers in health and social care* in 2006. [AQ4] This Guideline, at 392 pages, is for 'health and social care staff who work with people with dementia and their carers, and those who work with older people and people with learning disabilities' (NICE, 2006).

These guidelines were purposefully selected for the following reasons: the RUSA Guidelines are published by the American Library Association and therefore hold a prominent position for the training and evaluation of librarians and libraries in North America. The NICE Guidelines originate with the NICE in the UK; they are therefore authoritative,

form the basis for accreditation and evaluation programmes in UK healthcare, and draw extensively on cited empirical evidence.

The authors independently read through RUSA's *Guidelines for behavioral performance of reference and information service providers* and NICE's *Guideline on supporting people with dementia and their carers in health and social care*. The application of the four principles and four phases began to structure our iterative readings of the Guidelines and provided an organizational core for our evolving observations. Each of the Guidelines was read for indications, manifestations, or absences of the four moral principles and corresponding phases of care were. The principles and phases were also used to examine and compare the degree to which each guideline framed the complex interactions between information, communication, and dementia and to understand the ways in which care is expressed (and is captured) in each of these documents. The authors met frequently to discuss questions, confusions, as well as similarities and contrasts between the documents.

Findings

As we sought to understand what communicative interactions 'look like' in each of these guidelines, we uncovered a significant overlap between the communicative practices of librarians and healthcare professionals. While from different domains, both sets of Guidelines establish a rubric of procedures for dealing with interactions that could, in both cases, be complex and frightening, both for the service provider (librarian or dementia care worker) and the service recipient (library patron or individual living with dementia). We also discovered, in both sets of Guidelines, an underlying ethic of care: a repeated insistence upon embedding procedures within behaviour that manifests attentiveness, responsibility, responsiveness, and competence. The similarities and differences between the articulation of each principle is revealing.

Attentiveness

The element of attentiveness was present and prominent in both guidelines. NICE *Guideline* 1.1.1.4 advises that 'Health and social care staff should identify the specific needs of people with dementia and their carers arising from ill health, physical disability, sensory impairment, communication difficulties, problems with nutrition, poor oral health and learning disabilities.' Similarly, RUSA's Guidelines offer the following recommendations for information professionals: 'Identifies patrons needing or wanting help' (1.2.4) and 'Identifies the goals or objectives of the patron's research, when appropriate' (3.1.4).

Both healthcare and for information professionals, then, are encouraged 'to suspend one's own goals, ambitions, plans of life and concerns, in order to recognise and to be attentive to others' (Tronto, 1993a, p. 127). The Guidelines, in their emphasis on this point, implicitly acknowledge how easily the service provider can allow concerns of scheduling, logistics, time management, and personal reluctance to divert the attention from the needs of the service recipient.

We detect, also, a subtle difference. In its emphasis on 'ill health, physical disability and learning disabilities', the NICE Guideline frames the specificity of the individual in part as 'noise' that disrupts the true 'signal' of the person's life. Ideally, the service provider will see past the noise to alleviate a recognizable complaint, enabling the individual to live in reasonable comfort and contentment. And within a long-term care facility, the individual's

most important needs are commonly held, generalized needs that can be met by the facility: the need for comfort, safety, medical care, community, and the necessities of life. The RUSA Guidelines, on the other hand, frame the need itself as the signal: the service professional may well encounter hostility, confusion, or anxiety, but the professional should see past those manifestations and address the patron's specific information need: a need determined by the patron's individual circumstances, and often defiantly resistant to any form of classification or generalization. Library weblogs frequently collect such questions as: 'Why do 18th-century paintings have so many squirrels in them, and how did they tame them so as not to bite the painter?' (Keyser, 2014).

In the NICE Guidelines, attentiveness requires one to pierce through the specific behaviour to discover and address a general and widely shared need. In the RUSA Guidelines, attentiveness requires one to penetrate familiar patterns of recurring behaviour to address a highly specific need.

Responsibility

Responsibility was also apparent, with both guidelines prompting healthcare and information professionals to move towards involvement, acting on the different needs identified while being attentive. NICE Guideline 1.7.3.2 states that 'Health and social care staff should be trained to anticipate behaviour that challenges and how to manage violence, aggression and extreme agitation.' Guideline 1.11.2.1 states, 'Those carrying out carers' assessment should seek to identify any psychological distress and the psychosocial impact on the carer. This should be an ongoing process and should include any period after the person with dementia has entered residential care.' The RUSA Guidelines emphasize a similar readiness:

In order to have a successful reference transaction, it is essential that the reference librarian be approachable. Whether acting in a traditional/in-person role or a remote/virtual role, the librarian's first step in initiating the reference transaction is to make the patron feel comfortable in a situation that can be perceived as intimidating, confusing, or overwhelming. The librarian's initial response in any reference situation sets the tone for the entire communication process and influences the depth and level of interaction.

In both documents, the professionals' work moves to a more personal and perhaps even emotional involvement that is necessary to 'care well' (Tronto, 1993a, pp. 131–132). This involvement typically manifests as conscious and willed behaviour on the part of the carer or the reference librarian, while always aware that this behaviour sets the tone for the entire transaction.

Again, we detected a subtle difference. The NICE Guidelines emphasize a proactive response to behaviours and conditions before they become harmful and disruptive. Caregiving in dementia settings, it seems, entails a willingness to act swiftly. The RUSA Guidelines, on the other hand, emphasize a beneficial 'passivity': an active openness that invites the patron to come forward with an expression of need.

Responsiveness

Responsiveness was visible in both documents, with evidence that healthcare and information professionals are taking into consideration the care receiver's experience (whether

a library patron or an individual living with dementia), providing the opportunity to change care to make the experience more productive. As illustrated in RUSA Guidelines 4.1.4 and 4.1.5, information professionals ‘Work with the patron to evaluate results, revise search terms, and identify other sources to try if the search is unsuccessful’ and ‘Work with the patron to narrow or broaden the topic when too little or too much information is identified’. NICE cautions that

The experience of the diagnosis of dementia is challenging both for people with dementia and family members and for healthcare professionals, so healthcare professionals should make time available to discuss the diagnosis and its implications with the person with dementia and also with family members (usually only with the consent of the person with dementia). Healthcare professionals should be aware that people with dementia and family members may need ongoing support to cope with the difficulties presented by the diagnosis. (1.4.6.1)

In both cases, the procedures and processes involve a combination of feedback and adaptation, often repeated continuously. The NICE Guidelines, however, implicitly assume that this iterative process of care and adaptation will take place over an extended period, during which the resident and the caregiver will interact repeatedly, often at the same time and in similar circumstances. The RUSA Guidelines, on the other hand, frame the procedure within a one-time reference interview: while some patrons may request, and be given, repeated reference support, librarianship guidelines typically assume that the success or failure of the transaction will rest upon a single interview.

Competence

Paying regard to the outcome of the healthcare or the reference interaction was also visible in both guidelines, giving evidence of the element of competence. RUSA’s Guideline 3.1.5 prompts information professionals to ‘Rephrase the question or request and asks for confirmation to ensure accurate understanding’. Similarly, dementia care professionals are instructed to

identify, monitor and address environmental, physical health and psychosocial factors that may increase the likelihood of behaviour that challenges, especially violence and aggression, and the risk of harm to self or others. These factors include: overcrowding, lack of privacy, lack of activities, inadequate staff attention, poor communication between the person with dementia and staff, conflicts between staff and carers, weak clinical leadership. (1.7.3.1)

Both guidelines define competence as the scrutiny of the results of an interaction, gauging the degree of success, and adapting either one’s behaviour or the environmental conditions to improve the outcome of the interaction.

Discussion

The similarities between the two sets of Guidelines, structured through the use of the ethic of care elements, suggest that librarianship and dementia care share an obligation to take up the four ethical elements and perform necessary and important communicative tasks, with

sympathy, tact, and respect, emphasizing and recognizing the rights and the feelings of the service recipient.

Differences: Attentiveness, responsibility, and responsiveness

Despite these similarities, the Guidelines for reference service and for dementia care contain some intriguing differences, perhaps indicative that the four ethical elements resonate to different degrees within each of the Guidelines and their respective disciplines. The general RUSA Guidelines place great emphasis on being approachable, displaying interest, using good listening and inquiring skills, and following up the reference interview, coupled with understandable need for adept searching skills. The NICE Guidelines, on the other hand, place primary emphasis on clinically based procedures for diagnosing specific conditions, allowing for diversity of needs (such as diet, religion, and sexuality), obtaining valid consent, responding to non-cognitive symptoms, and ensuring equitable access to services (NICE, 2006), coupled with the understandable need to treat all residents with respect at all times.

In addition, the RUSA Guidelines frame 'care' specifically as empathy: attention, listening, and approachability, all tempered with an affective awareness. While RUSA's (2015) more specialized guidelines on reference services for health and medical reference service place a greater emphasis on the importance of accessing reliable and authoritative information, in both sets of guidelines, the process of caring is largely one of communicating non-judgemental, non-threatening, tactful openness intended to establish, on the part of the service recipient, trust and a willingness to share needs openly. The NICE Guidelines frame 'care' in a more multifaceted fashion. The quality of respect goes beyond the immediate interaction. It involves ensuring that the individual's rights are formally respected; it involves diagnosing the individual's condition accurately, promptly, and fully; it involves ensuring that appropriate consent has been obtained for all procedures; it involves ensuring that care workers are properly trained for their tasks; it ensures that multiple health services for an individual are accurately and appropriately coordinated (NICE, 2006). In the NICE Guidelines, 'care' is a less affective, more abstract concept, in which care manifests itself through sets of procedures that ensure, regardless of the emotional tone of individual interactions, that the needs of the individual with dementia remain paramount and are not submerged in the inevitable complexities and logistics of administering long-term care.

Similarities: Competence

We would like to suggest, however, that the connection between information reference work and dementia care goes deeper than the surface similarities that first inspired our investigation. In our comparison of the two guidelines, we discovered that the RUSA and NICE Guidelines connect most profoundly in Tronto's principle of 'competence'.

To begin with, both guidelines frame competence as a combination of the other three principles. To conduct a competent reference interview is to take upon oneself the responsibility to listen attentively to the inquiry and to use all one's skill and knowledge to respond in an appropriate manner. To provide adequate care to people living with dementia is to be attentive to the variety of environmental influences acting upon the residents, as well as to the symptoms of need that they manifest, and to use established procedures to respond appropriately. In an ethic of care context, the 'competence' of the reference librarian or the

care worker depends on the degree to which either one manifests the combination of attentiveness, responsibility, and responsiveness.

The emphasis upon empathy, in the RUSA Guidelines, and on correct completion of established procedures, in the NICE Guidelines, suggests something surprising: that neither guideline can accurately or completely define a good result. Upon reading the RUSA Guidelines, we are unsure what constitutes a 'correct' answer to a reference inquiry; upon reading the NICE Guidelines, we are unsure what constitutes a universally correct response to a given problem. In both guidelines, we discovered an underlying perplexity: a tacit awareness that both providing reference service and providing care to those with dementia contain more questions than answers. As such, both professions require a willingness to work with mysteries, follow clues, form deductions, and sometimes make educated guesses.

In such environments, competence, as one principle of an ethic of care, does not consist of having all the answers or implementing solutions flawlessly. Rather, competence emerges from these guidelines as a combination of the following:

- **attentiveness:** a willingness to monitor and keep track of every shred of evidence, however seemingly minor, that could provide a clue to the care recipient's or library patron's needs or concerns;
- **responsiveness:** a willingness to monitor closely the results of any intervention, and, if unsatisfactory, adjust the parameters, and then try again;
- **responsibility:** a willingness to act in the interests of the care recipient or library patron under conditions of perplexity and doubt, and sometimes in the face of threatening or abusive behaviour.

Whether emphasizing empathy, as do the RUSA Guidelines, or careful adherence to established procedures and documentation, as do the NICE Guidelines, both guidelines, and the communities that wrote them, aim to provide an adequate scaffolding that will enable service providers to show up and do their best under conditions of potential confusion, perplexity, and stress.

Conclusions

This exploratory study has charted some of the similarities and differences in communicative acts in library studies and dementia studies, as articulated in a set of widely used guidelines for each domain. Our comparison, however, makes no pretensions to generalizability, nor to characterize either reference service or healthcare as a monolithic, consistent practice that is covered by these guidelines. Further studies are needed to evaluate to what extent these centrally formulated statements of principle are actually applied in various diverse fields of action.

In both domains, the Guidelines frame the acts of communication between the service provider and the service recipient as multifaceted and potentially complicated. An ethic of care lens on both sets of Guidelines acknowledges the profound moral responsibility to safeguard both parties from the consequences of transactions that may manifest as confusion, misunderstanding, or potential hostility. Tracing the communicative interactions within the RUSA and NICE Guidelines using an ethic of care lens kept and held care as central to our analysis which facilitated some fascinating insights and prompts for future research. We wonder, for example, whether the connections that we unearthed under

Tronto's moral principle of 'competence' might serve as an interesting departure point for future studies that examine codified, documented care procedures. It is our hope that our relatively novel methods and findings (particularly for LIS) serve as a prompt for others in the library, information, and health communities to take up an ethic of care as a rich analytical tool and a helpful way to understand and elucidate 'communication accidents' (Dewdney & Michell, 1996).

Declaration of conflicting interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: Funding for this project received from Insight Development Grant from the Social Sciences and Research Council of Canada (SSHRC).

Note

1. Tronto (2013) has since added a fifth phase of care, *caring with* (solidarity), that underlines the importance of trusting and empathetic relationships and requires that the need for care and the way in which these needs are met are consistent with democratic commitments to justice, equality, and freedom.

ORCID iD

Nicole K Dalmer  <http://orcid.org/0000-0002-0326-4293>

References

- alz+. (2017, January 20). Moody & aggressive behaviors [Blog post]. Retrieved from https://www.alzconnected.org/WorkArea/threadeddisc/print_thread.aspx?id=77&g=posts&t=2147531366
- Alzheimer Society of Canada. (2010). *Rising tide: The impact of dementia on Canadian society*. Retrieved from http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC_Rising%20Tide-Executive%20Summary_Eng.ashx
- Astell, A., Alm, N., Gowans, G., Ellis, M., Dye, R., & Vaughan, P. (2009). Involving older people with dementia and their carers in designing computer based support systems: Some methodological considerations. *Universal Access in the Information Society*, 8(1), 49.
- Barnes, M. (2012). *Care in everyday life: An ethic of care in practice*. Bristol, UK: Policy Press.
- Barnes, M., & Brannelly, T. (2008). Achieving care and social justice for people with dementia. *Nursing Ethics*, 15(3), 384–395.
- Barnes, M., Brannelly, T., Ward, L., & Ward, N. (Eds.). (2015). *Ethics of care: Critical advances in international perspective*. Chicago, IL: Policy Press.
- Barnes, M., Henwood, F., & Smith, N. (2016). Information and care: A relational approach. *Dementia*, 15(4), 510–525.
- Bawden, D., & Robinson, L. (2009). The dark side of information: Overload, anxiety and other paradoxes and pathologies. *Journal of Information Science*, 35(2), 180–191.
- Boots, L. M., de Vugt, M. E., Withagen, H. E., Kempen, G. I., & Verhey, F. R. (2016). Development and initial evaluation of the web-based self-management program "partner in balance" for family

- caregivers of people with early stage dementia: An exploratory mixed-methods study. *JMIR Research Protocols*, 5(1), ■. **[AQ5]**
- Brannelly, T., (2006). Negotiating ethics in dementia care: An analysis of an ethic of care in practice. *Dementia*, 5(2), 197–212.
- Brannelly, T. (2016). Citizenship and people living with dementia: A case for the ethics of care. *Dementia*, 15(3), 304–314.
- Brooker, D. (2003). What is person-centred care in dementia? *Reviews in Clinical Gerontology*, 13(3), 215–222. **[AQ6]**
- Campbell, D. G. (2007, March 22). *Utilizing ritual in the design of information spaces for cognitively impaired*. Paper presented at Enriching Information Architecture: IA Summit, Las Vegas, Nevada.
- Chenoweth, L., King, M. T., Jeon, Y.-H., Brodaty, H., Stein-Parbury, J., Norman, R., . . . Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: A cluster-randomised trial. *The Lancet Neurology*, 8(4), 317–325.
- CILIP (Chartered Institute for Library and Information Science Professionals). (2014). Sharing positive connections. *CILIP Update*, 13.
- Cochrane, S., Knocker, S., & Towers, H. (2014). Opening doors to people living with dementia. *CILIP Update*, 36–38.
- Cohen-Mansfield, J., Libin, A., & Marx, M. S. (2007). Nonpharmacological treatment of agitation: A controlled trial of systematic individualized intervention. *The Journal of Gerontology, Series A: Biological Sciences and Medical Sciences*, 62(8), 908–916. **[AQ7]**
- Dankowski, T. (2015). Stimulating minds. *American Libraries*, 46(1/2), 54–57.
- Demers, A. (2016). GreyMatters: An interactive tool for patients and their caregivers. *Journal of Consumer Health on the Internet*, 20(1–2), 79–87.
- Dewdney, P., & Michell, G. (1996). Oranges and peaches: Understanding communication accidents in the reference interview. *Reference Quarterly*, 35(4), 520–536.
- Erdelez, S., Howarth, L. C., & Gibson, T. (2015, November). *How can information science contribute to Alzheimer's disease research?* Panel Presented at the Annual Meeting of the Association for Information Science and Technology, St Louis, MO, USA.
- Farrow, M. (2013). User perceptions of a dementia risk reduction website and its promotion of behavior change. *JMIR Research Protocols*, 2(1), ■. **[AQ8]**
- Fisher, B., & Tronto, J. (1990). Toward a feminist theory of caring. In K. Abel & M. K. Nelson (Eds.), *Circles of care: Work and identity in women's lives* (pp. 35–62). Albany: State University of New York Press.
- Garner, J. D. (1999). *Fundamentals of feminist gerontology*. Binghamton, NY: The Haworth Press, Inc. **[AQ9]**
- Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. London, UK: Harvard University Press.
- Graham, H. (1983). Caring: A labour of love. In J. Finch & D. Groves (Eds.), *A labour of love: Women, work and caring* (pp. 13–30). London, UK: Routledge.
- Harland, J. A., & Bath, P. A. (2008). Understanding the information behaviours of carers of people with dementia: A critical review of models from information science. *Ageing and Mental Health*, 12(4), 467–477.
- Harland, J., Bath, P. A., Wainwright, A., & Seymour, J. (2017). Making sense of dementia. A phenomenographic study of the information behaviours of people diagnosed with dementia. *Aslib Journal of Information Management*, 69(3), 261–277.
- Harmeyer, D. (2016). Reference chat: Filling a space in a beautiful way. *The Reference Librarian*, 57(3), 254–263.
- Holstein, M., & Mitzen, P. (Eds.). (2001). *Ethics in community-based elder care*. New York, NY: Springer Publishing Company. **[AQ10]**

- Howarth, L. C., & Hendry, E. (2011). Recovering memory: Sense-making and recall strategies of individuals with mild cognitive impairment. *Proceedings of the American Society for Information Science and Technology*, 48(1), 1–3.
- Kenner, A. M. (2008). Securing the elderly body: Dementia, surveillance, and the politics of “aging in place.” *Surveillance & Society*, 5(3), 252–269.
- Keyser, H. (2014, December 24). *Hilarious questions posed to the NYPL pre-internet*. Retrieved from <http://mentalfloss.com/article/60857/hilarious-questions-posed-nypl-pre-internet>
- Kitwood, T. (1997). *Dementia reconsidered: The person comes first*. Buckingham, UK: Open University Press.
- Kuhlthau, C. C. (1988). Developing a model of the library search process: Cognitive and affective aspects. *RQ*, 232–242.
- Kuhlthau, C. C. (1991). Inside the search process: Information seeking from the user’s perspective. *Journal of the American Society for Information Science*, 42(5), 361–371.
- Kuhlthau, C. C. (1993). A principle of uncertainty for information seeking. *Journal of Documentation*, 49(4), 339–355.
- [AQ11]** Law, M., Baptiste, S., & Mills, J. (1995). Client-centred practice: What does it mean and does it make a difference? *Canadian Journal of Occupational Therapy*, 62(5), 250–257.
- McPherson, B., & Wister, A. (2008). *Aging as a social process: Canadian perspectives*. Don Mills, Canada: Oxford University Press.
- Mellon, C. A. (1986). Library anxiety: A grounded theory and its development. *College and Research Libraries*, 47(2), 160–155.
- Mortensen, H. A. (2007). Dementia: A challenge for public libraries? A challenge for librarians? *Focus on International Library & Information Work*, 38(3), 85–88.
- Morton-Chang, F. M. (2015). *Tipping points to institutional care for persons living with dementia: Analyzing the policy trajectory in Ontario* (Doctoral dissertation), University of Toronto, Canada.
- NICE (National Institute for Health and Clinical Excellence). (2006). *Guideline on supporting people with dementia and their carers in health and social care*. Retrieved from <https://www.nice.org.uk/guidance/cg42>
- Noddings, N. (1984). *Caring: A feminist approach to ethics*. Berkeley: University of California Press.
- Pennington, D. (2016, October). *Supporting workplace information needs of people with dementia*. ASIS&T Annual Meeting 2016 (pp. 1–7).
- Radford, M. L. (1993). *Relational aspects of reference interactions: A qualitative investigation of the perceptions of users and librarians in the academic library* (Unpublished doctoral dissertation), Rutgers, The State University of New Jersey.
- Radford, M. L. (1996). Communication theory applied to the reference encounter: An analysis of critical incidents. *The Library Quarterly*, 66(2), 123–137.
- Radford, M. L. (1998). Approach or avoidance? The role of nonverbal communication in the academic library user’s decision to initiate a reference encounter. *Library Trends*, 46(4), 699–717.
- Radford, M. L. (2006a). Encountering virtual users: A qualitative investigation of interpersonal communication in chat reference. *Journal of the Association for Information Science and Technology*, 57(8), 1046–1059.
- Radford, M. L. (2006b). Interpersonal communication in chat reference: Encounters with rude and impatient users. In R. D. Lankes, E. Abels, M. White, & S. N. Haque (Eds.), *The virtual reference desk: Creating a reference future* (pp. 41–73). New York, NY: Neal-Schuman Publishers.
- Reference and User Services Association (RUSA). (2011). *Guidelines for behavioral performance of reference and information service providers*. Retrieved from <http://www.ala.org/rusa/resources/guidelines/guidelinesbehavioral>
- Reference and User Services Association (RUSA). (2015). *Health and medical reference guidelines*. Retrieved from <http://www.ala.org/rusa/resources/guidelines/guidelinesmedical>

- Reference and User Services Association (RUSA). (2016). *Reference and User Services Association strategic plan, June 2015–July 2018*. Retrieved from <http://www.ala.org/rusa/sites/ala.org/rusa/files/content/about/rusa-strategic-plan.pdf>
- Riedner, M. B. (2015). Librarians' role as part of the care team for Alzheimer's patients. *Journal of Consumer Health on the Internet*, 19(2), 143–147.
- Rockwood, K., Richard, M., Leibman, C., Mucha, L., & Mitnitski, A. (2013). Staging dementia from symptom profiles on a care partner website. *Journal of Medical Internet Research*, 15(8), ■. [AQ12]
- Rockwood, K., Zeng, A., Leibman, C., Mucha, L., & Mitnitski, A. (2012). Validation of an informant-reported web-based data collection to assess dementia symptoms. *Journal of Medical Internet Research*, 14(2), ■. [AQ13]
- Rogers, C. (1961). *On becoming a person: A therapist's view of psychotherapy*. Boston, MA: Houghton Mifflin.
- Sevenhuijsen, S. (2003). The place of care: The relevance of the feminist ethic of care for social policy. *Feminist Theory*, 4(2), 179–197. [AQ14]
- Sloane, P. D., Hoeffler, B., Mitchell, C., McKenzie, D. A., Barrick, A. L., Rader, J., Koch, G. G. (2004). Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation, and discomfort in nursing home residents with dementia: A randomized, controlled trial. *Journal of the American Geriatrics Society*, 52(11), 1795–1804. [AQ15]
- Standing, G. (2001). Care work: Overcoming insecurity and neglect. In M. Daly (Ed.), *Care work: The quest for security* (pp. 15–31). Geneva, Switzerland: International Labour Office.
- Tronto, J. C. (1993a). *Moral boundaries: A political argument for an ethic of care*. London, UK: Routledge.
- Tronto, J. C. (1993b). Beyond gender difference to a theory of care. In M. J. Larrabee (Ed.), *An ethic of care: Feminist and interdisciplinary perspectives* (pp. 240–257). London, UK: Routledge.
- Tronto, J. C. (2001). An ethic of care. In M. B. Holstein & P. B. Mitzen (Eds.), *Ethics in community-based elder care* (pp. 60–68). New York, NY: Springer.
- Tronto, J. C. (2013). *Caring democracy: Markets, equality, and justice*. New York: New York University Press.
- United Nations. (2009). *World population ageing*. New York, NY: UN.
- Wackerbarth, S. B., & Johnson, M. M. S. (2002). Essential information and support needs of family caregivers. *Patient Education and Counseling*, 47(2), 95–100. DOI: 10.1016/S0738-3991(01)00194-X.
- Westbrook, L. (2015). “I’m not a social worker”: An information service model for working with patrons in crisis. *The Library Quarterly*, 85(1), 6–25. [AQ16]
- Wexler, M. (2004). Getting to know you: Making the connection. *Alzheimer's Care Today*, 5(1), 81–87.
- World Health Organization. (2015). *World report on ageing and health*. Geneva, Switzerland: World Health Organization.

Nicole K Dalmer (BSc, MLIS) is a doctoral candidate in the Faculty of Information and Media Studies at The University of Western Ontario where she researches the intersections of dementia care, ageing in place policy, and information work.

DG Campbell is Associate Professor of Library and Information Science in the Faculty of Information Studies. He received his PhD in English literature from Queen's University in 1990. His research interests include the development of information services for people living with dementia and their caregivers, information organization, and linked and big data systems.