Family Caregivers of Loved Ones with Dementia

Jeffrey Drivon

San José State University

INFO 200 - Dr. Kevin Bontenbal

December 7, 2020

Abstract

Family caregivers of loved ones with dementia are an information community. The majority of care that is given to individuals with dementia comes from family caregivers. The informational grounds from which information is sought out takes place the majority of the time through the Internet and other technological means such as unique apps which allow family caregivers to connect with others whom are going through similar issues. Through connecting with others with similar experiences, a family caregiver can come to find out all the options that are available to them to that can bring down stresses they carry and bring them to an understanding of how to deal with the changes that are taking place with their loved one.

What is the information profession's role in all of this? Professionals through research and digging into the experiences of family caregivers need to find resources and programs that could be offered to family caregivers to make sure their needs are being met. Libraries at the local levels could host seminars and activities for caregivers and their loved ones. Librarians need to show caregivers they have a vested interest to put forth the latest advancements of caregiving techniques to meet their needs of handling stress and loved ones every changing behaviors.

Introduction

The interest has been with me throughout life to assist and help others in need. It is what led me to become a teacher and coach. The subject of caregivers came about due to my family taking care of two grandparents who suffered through Alzheimer's and dementia. As Fisher and Bishop (2015) point out, "community can be thought of as an engine by which information services are developed and delivered" (p. 20). Bangerter et al. (2019) described how " family caregivers play a critical role in supporting the health, well-being, and quality of life for patients with chronic health conditions" (p.e11237). This research focuses on the top behaviors and needs of the family caregiver that is responsible for a loved one or ones with dementia. As Steiner et al. (2015) point out, "family members provide the majority of care for people with dementia, they are an essential resource for that person, as well as an asset to the healthcare system" (p.163). Furthermore, according to the Alzheimer's Association (2014), "eighty-five percent of help provided to older adults in the United States is from family members" (p. e61). In this day and age, the Internet proves to be a major contributor in the ways family caregivers seek answers to their most desirable needs. Techniques in treating changes in behaviors of loved ones and stress that consumes the caregiver will be discussed. Evolving technologies caregivers can use will be opened up to the reader and where family caregivers can obtain social support. The research began with the caregiver for a dementia patient from a generic viewpoint. The more in-depth I looked at articles dealing with both paid and unpaid family caregivers I narrowed the gap. The dementia patient is not just another human entity, but the loved one with dementia is someone to be loved, cared for unconditionally, and cherished. The wonderful aspect to the research is the discovery of much technological advancements caregivers can use to improve the quality of life for their loved ones and themselves. Regarding the dementia

recipient, Howrey (2018) states, “these individuals are an innovative and receptive target audience for library program planners and managers who hope to have an impact on health information literacy and the quality of life for families” (p.251). Libraries and librarians can provide the public with the promotion of different memory devices and techniques. According to Riedner (2015), “individual caregivers, memory care facilities, and adult daycare facilities are always looking for meaningful activities to engage, stimulate, and entertain diagnosed persons” (p.144). Kelsey (2018) communicates to his audience that programs are available for caregivers and patients alike that includes storytelling, memory kits for those with dementia and for caregivers, stuff animals, therapy animals, music programs, reading programs, the creation of stories through pictures, and vintage and antique items to promote memories and bring the senses alive.

Literature Review

Informational Needs of Family Caregivers of loved ones with dementia

Family caregivers proved to show needs in the area of their own stresses and how to deal with the changing behaviors of their loved ones the most. Steiner et al. (2015) conducted a study to help healthcare professionals and nurses understand needs so devices can be developed. The authors discussed, “family caregivers’ top information needs dealt mostly with behavior changes seen in the person which care was provided, such as forgetfulness/confusion and repeating questions/actions” (p.166). They also found that “caregivers also identified a need for more information on managing their own stress” (p.165). Wackerbarth and Johnson (2002) conducted a survey on a 3-point scale to show what the most informational needs were. It was determined, “the most important information would detail health plan coverage (mean=2.64) and how to find

the best health care (mean=2.63)" (p.97). Bangerter et al. (2019) while reviewing research completed by Wolff et al. (2016), describe how caregivers sought "information for themselves and others, indicating a dual purpose behind health information-seeking behavior" (p. e11237). Kazmar et al. (2013) received from caregivers, that they "learned the importance of shifting their attention to themselves for self-care, and their goals for themselves, rather than focusing only on the care of their CRs and setting goals for how the CRs should act" (p.195). CR refers to care recipients.

Information-Seeking Behavior of Caregivers

It is said by Ham (2020) that "caregiving comes with a high learning curve and responsibility for many people, but having the right information at the time of need can lead to better outcomes and improved quality of life for both the care recipient and the caregiver" (p.199). The author throughout the article describes numerous websites a caregiver can go to seek informational needs. One begins to see the Internet as the means by which caregivers seek information out. Furthermore, the Internet and electronic sources are the ways caregivers seek out information (Bangerter et al., 2019; Soong et al., 2020). It is important to point out as stated by Bangerter et al. (2019), "caregivers sought health information for themselves and used computers, smartphones, or other electronic means to find health information more frequently than noncaregivers" (p. e11237). One study tested out computer technologies through an app known as Yammer to help other caregivers see the experiences of others through micro-blogging (Pitts et al., 2017, p. 616-617). Another study found that using a Web-based resource, My Tools 4 Care, caregivers were willing to share their experiences, reflect on their experiences, gain other education and informational needs, and see other caregivers were having similar

experiences (Ploeg et al., 2018, p. 1). Efthymiou et al. (2017) conducted a study that shows eHealth literacy will become more prevalent. The authors conclude, "the usage of new technologies and the Internet could act as a facilitator in the caregiving demands of carers" (p. 89). When referring to a study conducted by Lam and Lam (2009), Efthymiou et al. (2017) describes, "the most common use of the Internet among carers in Australia included chat sites and emails, indicating carers' need to communicate" (p.89)

Applications Family Caregivers Can Use

Howarth (2020) touches on the fact that institutions, such as libraries and museums need to be able to be adaptable and offer support for those who suffer from cognitive disorders for the sake of "preserving and enhancing individual memory" (p. 21). The author comments on the fact that it is a matter of legality now to have particular programs in place to assist those individuals (p .21). One museum offered a monthly program, which experienced "outcomes uniformly assessed as intellectually stimulating, providing shared experiences and social interaction in an accepting environment" (p. 28). Goodall et al. (2019) conducted a study, which involved the sensory intervention SENSE-GARDEN with people with dementia (p. e14096). The purpose is to have those living with dementia take part in unique activities so the individual might be able to make particular connections. It was said, "by interacting with the various stimuli together with a caregiver, it is hoped that the PWD is able to reminisce on their past and become engaged in the *present moment*. The SENSE-GARDEN encourages PWDs to exercise at both mental and physical levels and takes them back into places they feel connected to (p. e14096). PWD refers to people with dementia.

Emerging Technologies To Assist Caregivers

Family caregivers can use robotic and other various types of advancements to improve the quality of life for loved ones. Yu et al. (2015) conducted a study with the robotic seal PARO. Individuals with dementia along with their caregivers were to be analyzed after an amount of time with PARO (p.1). Findings indicated levels of depression were down with those with dementia and burden that the caregivers carried were lower (p.1). Voller and Ory (2020) point out many products is made available for "intelligent assistive technology" (p. 191). Both the caregiver and the individual with dementia can wear products such as GPS devices, use mobility aids such as smart wheel chairs, and use hand held devices such as smart phones to ease burdens that are at hand. Online communities such as The Purple Sherpa (https://www.thepurplesherpa.org) provide information and caregiver support to those who seek direction and insight.

Methodology

The research process began using academic databases, EBSCOhost's Library and Information Science Source, National Library of Medicine, and Google Scholar. Information community, information needs, information-seeking behavior, dementia caregiver, dementia patient, family caregiver, Alzheimer's Disease, emerging technologies, dementia friendly communities are some of the key terms used when searching for articles. Community-based resources and other articles were obtained by using Google using terms like Alzheimer's, dementia online community, and words similar to the database search. Berger's *Contagious: Why Things Catch* was read and analyzed to get a sense of how libraries and librarians can grab the attention of those who seek information. Theoretical readings and insights about the library

and information science field were taking from the curriculum of San José State University's INFO-200:Information Communities. Reports on findings were also used of different aspects of the information community. Some information was obtained and written down in assignments on my blogging page on the San José State University's School of Information community site.

Discussion

Recognition of the Needs by Librarians To Provide Assistance

The aim with the above research was to understand the needs of family caregivers and the behaviors they exhibit so librarians know how to approach this particular community to provide these individuals with the most up-to-date information and data to alleviate changes for a loved one and lower the stress for the caregiver. O'Brien and Greyson (2018) tell us, "information need is a fundamental concept in library and information science (LIS). Human information needs form the basis of many types of information work" (p. 40). It is said, "if people did not have information needs, then libraries and other information systems would cease to exist, even basic interpersonal information would be altered" (Naumer & Fisher, 2017, p.2115). Furthermore, librarians need to discover what tools are out there so family caregivers can put those items to use. Information behavior, as described by Bates (2017), is "the many ways in which human beings interact with information, in particular, the ways in which people seek and utilize information" (p.2074). To reiterate, it is the librarian's duty to help caregivers and those with dementia find information they are seeking to find. As Cooke (2016) describes, "in the first (of eight) tenets of the American Library Association's (ALA) Code of Ethics (2008), it stated that librarians must 'provide the highest level of service to all library users through appropriate and usefully organize resources; equitable service policies; equitable access; and accurate,

unbiased, and courteous responses to all requests.'" (p. 1). But first, we need to see approaches the family caregiver takes to obtain information. Only then, can librarians take the appropriate actions necessary to assist family caregivers. As O'Brien and Greyson (2018) point out, "understanding the user's context is important not only in human response to information needs but also in the design of information systems" (p.43).

Behavior To Seek Information For Usage

Spink and Cole (2006) discuss four approaches, which include the problem solving approach, the everyday life information seeking (ELIS) approach, the foraging approach, and the modular thinking approach, on how individuals obtain information (p.31-32). In the problem solving approach, the "information seeking is purposive, we assume input data are gathering by the seeker in a specific context or situation for the purpose of creating information" (p.31). In his book, *Contagious: Why Things Catch On,* Berger (2013) shares that we need to pass on useful information so users can put it to use quickly (p. 173). I would argue that family caregivers flock to online communities for the purpose of being around others with similar situations so they can apply information received to bring understanding to the changes in their life. Thus, individuals connect with one of the five characteristics with information communities. Fisher et al. (2003) point, "information communities connect people and information, which contributes to the degree of social connectedness within a community" (p.303). By being around others with similar situations, stress levels may come down and new techniques can be applied to better improve behaviors of loved ones. Barber (2014) conveys, "there is no more powerful communication technique than one person talking with and listening to another, whether it's on social media (good) or live and in person (best)" (p.34)

ELIS as stated by Spink and Cole (2006), "is a combination of non-purposive and purposive information behavior. Inputs are bits and pieces of data the individual gathers both consciously and unconsciously for making sense of a problem situation" (p.31). I would argue that family caregivers use community-based sites such as The Purple Sherpa (https://www.thepurplesherpa.org) and the Alzheimer's Association (alz.org) to gather information about why this experience is happening. Both sites give facts of the disease, newsworthy articles, and the element of social connectedness. As Fisher et al. (2003) point out, "information communities involve the collaboration of a variety of organizations or groups that provide information, and may share joint responsibility and resources" (p. 300).

The process of foraging involves the element of maximizing gains (Spink & Cole, 2006, p. 31). Family caregivers come together to learn about the new emerging technologies that produce fruitful results that come from the global stage. Goodall et al. (2019) discussed the SENSE-GARDEN EU project, which created those virtual spaces that were relatable to the person with dementia regarding "personal memories and individual preferences of the users" (p.1). Botek (n.d.) told us about France involving Snoozelen rooms that involved multisensory stimuli to calm behaviors. Family caregivers can use these technologies to break through barriers of new information to ease the situation a hand and to harness the technology that is being shared throughout the world (Fisher et al., 2003, p.301-302).

Family Caregivers of Loved Ones With Dementia And Librarians

Fisher and Bishop (2015) said it best, "community can be thought of as an engine by which information services are developed and delivered" (p. 20). The more information family

caregivers can gain, the more information can be handed on to someone else. Christian and Levinson (2003) give insight into the four angles of community. Like an engine with its parts or components, each angle plays a role to keep information evolving and ultimately finding ways to see needs are met. The proximate angle is in play because caregivers come together looking for answers to meet the needs of their loved ones. One can see the primordial and instrumental angles are involved because of the love family caregivers have for their loved ones and the caregivers' goal of keeping them healthy and safe. I can argue the affinity angle is involved because of caregivers have a commonality of love and values towards their loved ones to get them to their final destination in a safe and respectable manner while caregivers' own stresses stay as mellowed as they can.

Barber (2014) proposes that libraries need to focus on what information they can provide to users to have them share the information with others. Howrey (2018) begins to highlight three strategies that would reach out to family caregivers (p. 252-253). They have to do with advocacy for caregiving public policy, resource building, and programming and education. Reidner (2015) suggests, "consumer health librarians can assume a role on the Alzheimer's care team, similar to that of art and music therapists, by promoting books and other library materials by persons diagnosed with dementia" (p. 143). Librarians need to become acquainted what they can offer the family caregiver community. They can take programs such as the Tales and Travel program to memory care facilities (p. 145). This program takes loved ones on an imaginary adventure and it highlights key facts. Other devices for family caregivers would include personalized kits, individual appointments to look through specialized materials, and marketing strategies. (p. 146). Even more than providing particular tools to family caregivers, librarians' emotions need to be

involved with this information community. Berger (2013) comments that it is all about "helping others feel good" (p.159). If we reflect back, one of the top needs of family caregivers is to manage stress. Librarians need to enter in to some degree into the family caregivers' world as in all subject matters. Berger sums up the principle of emotion by saying, " when we care, we share" (p. 96). As discussed early on in this research, Kelsey (2018) reminds us of the work numerous libraries are becoming involved in to offer their patrons various kits, pets or animals, and programs to engage both, the caregivers and loved ones with dementia. "Any effort you make to serve patrons with dementia, no matter how big or how small, makes a difference in their lives and for your community" (Kelsey, 2018).

Conclusion

Although there are many means of communicating and obtaining information, family caregivers use the Internet and other technological advancements the most to reach out to find the top needs to control their stress and also to gain an understanding of the unique behaviors of their loved ones with dementia. "An explicit information need is often considered to be the motivating force behind a user's action to seek information" (Naumer & Fisher, 2017, p. 2116). The information libraries seek out and pass on needs to have a sense of practical value for family caregivers. Berger (2013) shares that we need to pass on useful information so users can put it to use quickly (p. 173).

Information professionals and librarians will develop tutorial programs to provide caregivers the confidence in information-seeking skills through the Internet. "Making something more observable makes it easier to imitate" (Berger, 2013, p. 127). Information professionals will

create and seek out sources through social networks or the creation of health informational databases focusing on coping mechanisms to relieve stress and anxiety for family caregivers so they can give proper attention and care to their loved ones. Information professionals can turn to the concepts of accuracy, bias, and currency when pointing caregivers to informational sources and looking to organizations to put on seminars or programs that satisfy the informational needs of caregivers to counter the overwhelming amount of data on the Internet. Information professionals will seek to locate the best apps family caregivers can use to reflect and understand different behavior their loved ones exhibit. Most importantly, as Barber (2014) asks, “how can you inspire people to share their library stories” (p. 33)?

References

Alzheimer's Association. (2014). 2014 Alzheimer's disease facts and figures. *Alzheimer's and Dementia: The Journal of the Alzheimer's Association, 10*(2), e47-e92. https://doi.org/10.1016/j.jalz.2014.02.001

American Library Association. (2008). *Code of Ethics of the American Library Association.* http://www.ala.org/advocacy/sites/ala.org.advocacy/files/content/proethics/codeofethics/Code%20of%20Ethics%20of%20the%20American%20Library%20Association.pdf

Bangerter, L. R., Griffin, J., Harden, K., & Rutten, L. J. (2019). Health information-seeking behaviors of family caregivers: Analysis of the health information national trends survey. *JMIR aging*, *2*(1), e11237. https://doi.org/10.2196/11237

Barber, P. (2014, January/February). Contagious marketing: how libraries can get more word-of-mouth buzz. *American Library Magazine*. https://americanlibrariesmagazine.org/wp-content/uploads/2015/01/0114.pdf

Bates, M. J. (2017). Information behavior. In J. D. McDonald & M. Levine-Clark (Eds.), *Encyclopedia of Library and Information Sciences* (4th ed., pp. 2074-2085). CRC Press.

Retrieved September 11, 2020, from https://doi.org.libaccess.sjlibrary.org/10.1081/E-ELIS4

Berger, J. (2013). *Contagious: Why things catch on.* Simon & Schuster.

Botek, A. (2013, September 24*). How different countries infuse dignity into dementia care*. Aging Care. Retrieved November 12, 2020, from https://www.agingcare.com/articles/different-countries-making-dementia-care-dignified-161973.htm

Christensen, K., & Levinson, D. (2003). Introduction & reader's guide. In K. Christensen, & D. Levinson (Eds.), *Encyclopedia of community: from the village to the virtual world* (pp. xix- xxxvi). Sage Publications, Inc. Retrieved August 31, 2020, from http://dx.doi.org.libaccess.sjlibrary.org/10.4135/9781412952583

Cooke, N. A. (2016). *Information Services to Diverse Populations: Developing Culturally Competent Library Professionals*. ProQuest Ebook Central. https://ebookcentral.proquest.com

Efthymiou, A., Middleton, N., Charalambous, A., & Papastavrou, E. (2017). The association of health literacy and electronic health literacy with self-efficacy, coping, and caregiving perceptions among carers of people with dementia: Research protocol for a descriptive correlational study. *JMIR research protocols*, *6*(11), e221. https://doi.org/10.2196/resprot.8080

Fisher, K.E. & Bishop, A.P. (2015). I*nformation communities: defining the focus of information service.* In S. Hirsh (Ed.), Information services today (pp. 20-26). Rowman

& Littlefield Publishers.

https://ebookcentral.proquest.com/lib/sjsu/detail.action?docID=2032756

Fisher, K., Unruh, T., & Durrance, J. (2003). Information communities: characteristics gleaned from studies of three online networks. In R. Todd (Ed.), *Proceedings of the 66th annual meeting of the american society for information science & technology* (pp. 298–305). Medford, NJ: Information Today.

Goodall, G., Ciobanu, I., Taraldsen, K., Sørgaard, J., Marin, A., Draghici, R., Zamfir, M. V., Berteanu, M., Maetzler, W., & Serrano, J. A. (2019). The use of virtual and immersive technology in creating personalized multisensory spaces for people living with dementia (sense-garden): Protocol for a multisite before-after trial. *JMIR research protocols*, *8*(9), e14096. https://doi.org/10.2196/14096

Ham, K. (2020). Wayfinding along the caregiving journey: Resources for informal caregivers. *Journal of Consumer Health on the Internet, 24(2)*, 186-200. https://doi.org/10.1080/15398285.2020.1753999

Howarth, L.C. (2020). Dementia friendly memory institutions: Designing a future for remembering. The International Journal of Information, Diversity, & Inclusion, 4(1), 20-41. https://doi.org/10.33137/ijidi.v4i1.32529

Howrey, M. (2018). Health sciences library outreach to family caregivers: a call to service. *Journal of the Medical Library Association, 106*(2), 251–258. https://doi.org/10.5195/jmla.2018.390

Kazmar, M.M,, Glueckauf, R.L., Ma, J., & Burnett, K. (2013).Information use environments of African-American dementia caregivers over the course of cognitive–behavioral therapy for depression. *Library & Information Science Research, 35*(3), 191-199. https://doi.org/10.1016/j.lisr.2013.02.003

Kelsey, D. J. (2018). Reaching for memories: Expanding services and programming to patrons living with alzheimer's disease. *Public Libraries Online.* http://publiclibrariesonline.org/2018/11/reaching-for-memories-expanding-services-and-programming-to-patrons-living-with-alzheimers-disease/

Lam, L., & Lam, M. (2009). The use of information technology and mental health among older care-givers in Australia. *Aging & mental health*, *13*(4), 557–562. https://doi.org/10.1080/13607860802607306

Naumer, C.M & Fisher, K.E. (2017). Information needs. In J. D. McDonald & M. Levine-Clark (Eds.), *Encyclopedia of Library and Information Sciences.* (p. 2115-2121). CRC Press. Retrieved September 21, 2020, from https://doiorg.libaccess.sjlibrary.org/10.1081/E-ELIS4

O'Brien, H. & Greyson, D. (2018). Diverse information needs. In S. Hirsh (Ed.), *Information Services Today : An Introduction*. (p. 40-51). ProQuest Ebook Central. Retrieved September 21, 2020, from https://ebookcentral.proquest.com

Pitts, K., Pudney, K., Zachos, K., Maiden, N., Krogstie, B.R., Jones, S., Rose, M., MacManus, J., & Turner, I. (2015). Using mobile devices and apps to support reflective learning about older people with dementia. *Behaviour & Information Technology, 34*, 613 - 631. https://doi.org/10.1080/0144929X.2015.1015165

Ploeg, J., McAiney, C., Duggleby, W., Chambers, T., Lam, A., Peacock, S., Fisher, K., Forbes, D. A., Ghosh, S., Markle-Reid, M., Triscott, J., & Williams, A. (2018). A web-based intervention to help caregivers of older adults with dementia and multiple chronic conditions: Qualitative study. *JMIR aging*, *1*(1), e2. https://doi.org/10.2196/aging.8475

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. https://doi.org/10.1080/15398285.2015.1026712

Soong, A., Au, S. T., Kyaw, B. M., Theng, Y. L., & Car, L. T. (2020). Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: a scoping review. *BMC Geriatrics, 20*(1), Article 61. https://doi.org/10.1186/s12877-020-1454-y

Spink, A. and Cole, C. (2006), Human information behavior: Integrating diverse approaches and information use. *Journal of the American Society for Information Science and Technology*, *57*(1), 25-35. https://doi.org/10.1002/asi.20249

Steiner, V., Pierce, L. L., & Salvador, D. (2016). Information needs of family caregivers of people with dementia. *Rehabilitation Nursing : The Official Journal of the Association of Rehabilitation Nurses*, *41*(3), 162–169. https://doi.org/10.1002/rnj.214

The Purple Sherpa (n.d.). *Supporting you*. Retrieved December 20, 2020, from https://www.thepurplesherpa.org

Vollmer D. D., & Ory, M. G. (2020). Emerging issues of intelligent assistive technology use among people with dementia and their caregivers: A u.s. perspective. *Frontiers in Public Health*, *8*, 191. https://doi.org/10.3389/fpubh.2020.00191

Wackerbarth, S. B., & Johnson, M. M. (2002). Essential information and support needs of family caregivers. *Patient education and counseling*, *47*(2), 95–100. https://doi.org/10.1016/s0738-3991(01)00194-x

Wolff, J. L., Darer, J. D., & Larsen, K. L. (2016). Family caregivers and consumer health information technology. *Journal of General Internal Medicine*, *31*(1), 117–121. https://doi.org/10.1007/s11606-015-3494-0

Yu, R., Hui, E., Lee, J., Poon, D., Ng, A., Sit, K., Ip, K., Yeung, F., Wong, M., Shibata, T., & Woo, J. (2015). Use of a therapeutic, socially assistive pet robot (PARO) in improving mood and stimulating social interaction and communication for people with dementia: Study protocol for a randomized controlled trial. *JMIR Research Protocols*, *4*(2), e45. https://doi.org/10.2196/resprot.4189