The Role Support Networks Play in the Lives of Informal Caregivers of People Living with Dementia

By

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Abstract

There is a recognition that with an increase in the proportion of the population living with dementia there will also be increased demands on informal caregivers. Informal caregivers provide the majority of care to people living with dementia and there is significant physical and emotional stress that is associated with the caregiving role. This study engaged informal caregivers of people living with dementia directly and asked what is the role that support networks in their lives. Two sub questions were also posed: how do informal caregivers see support and what factors influence the role of support networks.

Based within an ecological framework, a qualitative descriptive methodology was used to collect the insights and experiences of informal caregivers of people living with dementia. Purposeful sampling was used to recruit informal caregivers who were able to share their experience of their support networks. Six participants were recruited and they participated in two semi-structured face to face interviews each at two different times. The interviews were audio recorded. Data analysis involved reviewing the twelve transcribed interviews for significant events and concepts, and grouping events with similarities and differences. These groups were reviewed and the findings revealed the membership of the support networks as well as responding to the main research question and the two sub questions.

The findings report that caregivers identified four consistent members of their support networks. They are family, friends/community, healthcare providers and formal support groups. The findings for how informal caregivers see support produced four characteristics. These are: 1) support needs to come from all levels; 2) help that is offered without the caregiver asking has a big impact on the caregiver's sense of support; 3) when others understand dementia and have skills in interacting with the person living with dementia this increases the caregivers sense of support; and 4) when support networks assisted in accessing and implementing resources this also increased the caregivers sense of support.

The four factors that influence the role of support networks that caregivers identified were: 1) the loss of the core member of their network to the diagnosis of dementia; 2) the worry of caregivers that they are increasing the burden on their family when they ask for help; 3) the withdrawal of the community from their network; and 4) how their personal philosophies about caregiving influenced their sense of support.

The findings for the two sub questions provide the context of the five major roles which asked what is the role of support networks in the lives of informal caregivers of people living with dementia. These themes are: 1) participation in advocacy to address the stigma of a dementia diagnosis; 2) to understand and help others understand dementia; 3) to assist in accessing and coordinating resources; 4) to provide care to the person with dementia; and 5) to help to coordinate support at all levels.

The conclusions are that while the literature describes each of these themes, hearing directly from informal caregivers about the role of their support networks was absent. As well the role of the community in support networks has not been extensively explored in the literature. Two areas of new knowledge emerged from this research. They are: 1) the recognition that the support of the community is a key element in informal caregiver's sense of support but the community has often withdrawn and is absent as a member of the support network; and 2) support at all levels is critical and the informal caregiver's description of these areas adds a clearer picture of how this broader support contributes to their overall sense of support.

Preface

This thesis is an original work by Helen Lightfoot. The research project received research ethics approval from the University of Alberta Research Ethics Board, Project Name "The Role Support Networks Play in the Lives of Informal Caregivers of People Living with Dementia," No. Pro0081206, May 22, 2018.

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My first thank you must be extended to the six participants who opened their homes, hearts and minds and shared their valuable knowledge. Participating in this study added to their strenuous workloads of caregiving. Their perspective has enabled us to look outside of the direct caregiving role for ways to provide support through family, friends and communities.

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Family has been a wonderful support through this journey also. My husband’s encouragement and listening ear gave me the energy to stay focused on my studies. My three young adult children have been cheerleaders and computer consultants throughout the last three years.

Both of my parents provided strong values of appreciating education and contributing to the support and care for others. I had the privilege of supporting my mother to be the caregiver for my father who had dementia and cancer and my mom’s perspectives and insights set the stage for my research question. She is an independent 90-year-old, living in her own home, making friends of all ages and continuing to teach all her children and grandchildren what it means to grow older while living life to the fullest.

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Chapter 1: Introduction

Research Question and Purpose

There is an increasing number of people living with dementia due to two population trends. First, the proportion of the general population that is elderly is growing worldwide (Gallagher-Thompson et al., 2012) and second there is an increase in the number of people receiving a diagnosis of dementia because advancing age is the greatest risk factor for dementia (Alzheimer Society, Alberta and Northwest Territories, 2017). These two factors point to an increase in the number of people living with dementia and consequently an increased demand for informal caregivers to meet these needs. Informal caregivers, who may be spouses, partners and/or children, provide the majority of the physical and emotional care for people living with dementia (Alzheimer Society, Alberta and Northwest Territories, 2017; Williams et al., 2016). Informal caregivers experience significant negative physical and emotional impacts during their time of caregiving (Chappell & Funk, 2011) and there is a recognition that resilient support networks can help informal caregivers mitigate the mental and physical stress of providing care over a long period of time (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2011). There is a strong identified trend towards informal caregivers becoming more socially isolated with the progression of dementia of their loved ones. The experiences and insights of informal caregivers can help us understand how to start addressing social isolation, what role their support networks play in this process and what further supports are needed to build and sustain resilient networks. There appears to be a gap in the literature about the first-hand experience, insights and knowledge of informal caregivers about the role support networks play for them. This knowledge could add to the understanding of the policies and structures that support caregiving and the well-being of caregivers. The health and well-being of caregivers is essential to maximize the ability of people living with dementia to live within the community and minimize their reliance on formal health systems (Lopez-Hartmann, Wens, Verhoeven, & Remmen, 2012).

The research question guiding this study is: what is the role of support networks in the lives of informal caregivers of people living with dementia? Two sub questions allow further exploration of this question: 1) how do caregivers see support, and 2) what factors influence the role of support networks. It also asks informal caregivers who they identify as being part of their support network. Through face to face interviews with informal caregivers, I determined if they have a social network and if it has changed through the progression of their loved one's disease process, in what ways it has changed, as well I explored the importance of the social network in their lives. It is my hope that their knowledge and insights add to the scholarly and practical discussions in the growing area of care for informal caregivers of people living with dementia.

Personal Positionality

It is acknowledged that the position and relationship of the researcher to the topic and community being studied impacts the research process and its' outcomes (Berger, 2015). My relationship to researching the role of support networks for informal caregivers of people living with dementia intersects with both my personal and my professional arenas. I have worked for twenty-five years in the area of home care as a front-line case manager, education lead and manager. These roles have allowed me the privilege of meeting and listening to the experiences of hundreds of informal caregivers and people living with dementia. This experience has helped me to build a significant depth of knowledge in working in this area. It is my experience that these professional roles also have a power inequity within them. Caregivers and people living with dementia are requesting access to services in programs where I play a gatekeeping role. Overt acknowledgement of this power differential and recognition of the skill and expertise of informal caregivers, supports my ability to be aware of and open to the impact of these power differences.

I have also been a family member who cared for a parent living with dementia. My father lived with dementia for many years and my mother was his primary caregiver. The experience of supporting both parents through this dementia journey has given me a very personal perspective of the stressors and joys involved in it. The need to be aware of my biases and assumptions from this personal experience requires a constant and deliberate effort to continually examine my view and listen for different and similar ideas in the data.

Reflection on the literature about support networks for informal caregivers of people with dementia has facilitated my understanding of the complexity and multifaceted nature of this topic. My work and personal experience, while enriching my understanding of the research question, also makes it more difficult to recognize the biases that I bring.

This research brings the perspective of informal caregivers of people living with dementia to the question: what is the role of support networks in their lives? This perspective will contribute to the knowledge of how to develop and sustain resilient support networks. The next section will review the literature that contributes to understanding support networks.

Chapter 2: Literature Review

The global aging of the population continues to grow and the associated increase in dementia rates is challenging informal caregivers, health providers and communities to be creative in meeting the needs of those living with dementia. Globally there are 36 million people living with dementia and this is expected to grow to 66 million by 2030 (Gallagher-Thompson et al., 2012). Today there are approximately 500,000 Canadians living with dementia and this number will double by 2038 (Schroeder, MacDonald, & Shamian, 2011). Care for persons living with dementia is primarily provided by informal caregivers (Tomita, Lee, Lee, Russ, & Noe, 2010). Lopez-Hartmann, Wens, Verhoeven, and Remmen's (2011) define an informal caregiver "as a person who provides care to a relative, friend or neighbor in need of long-term care on a regular basis, not through a professional or volunteer organization. There has to be a personal relationship between the caregiver and the care recipient" (p. 2). The impact of this caregiving role is felt in many aspects of the caregiver's life. Financial, emotional, physical and psychological stressors have been recognized as significant barriers in maintaining the caregiver role (Shahly, Chatterji et al., 2012; Shroeder et al. 2011).

Efforts to support informal caregivers have traditionally emerged from the health care system (Gallagher-Thompson et al., 2012). This relies on the medical model process in which a problem is identified, an assessment is completed to determine the cause and finally a solution is prescribed to address the cause. This has, however, restricted the approaches that can be implemented to benefit informal caregivers. Individual support, community collaboration and proactive policy need to be explored to start to meet the growing needs of informal caregivers of persons living with dementia (Crampton, & Eley, 2013; Kerr Robertson, 2014; Sorenson, Pinquart, & Duberstein, 2002).

The literature review begins with a description of how informal caregivers define meaningful social support and the strategies they employ to assist in sustaining their caregiving role. This is followed by a review of the factors that affect the ability of informal caregivers to cope. These factors help to identify what interventions and supports are necessary to help them in their caregiving role. A description of the membership and roles of support networks, how they connect caregivers to communities and the communities' potential to increase the informal caregiver's ability to cope is the next area of exploration. This leads to a discussion of community support in the development and sustainability of networks for informal caregivers. A range of models of care are explored that look at the physical environment and the collaboration of key stakeholders as key components of community support. The final section looks at the existing Canadian policies which support informal caregivers and barriers that exist in establishing support networks.

This review on how informal caregivers define effective support from their network, focuses on the expressed experiences and opinions of informal caregivers and what they have begun to identify as helpful in their caregiving role. There was very little content in the literature where the direct input of informal caregivers about support was sought (Gethin-Jones, 2014; Hofacker, Boyken, & Eisenstein, 2016) but there are numerous studies and reviews that include informal caregiver feedback in their methodology. This included surveys that were primarily focused on a specific aspect of informal caregiving such as health (Jowsey, McRae, Gillespie, Canfield, & Yen, 2013), caregiver burden (Shahly et al, 2013), respite care (Salin, Kaunonen, & Astedt-Kurki, 2009) or quality of life (Ratcliffe, Lester, Cozener, & Crotty, 2012). Within the context of the specific topic these surveys asked informal caregiver's views on support. There was also a number of reviews and survey-based research that focused on a specific topic including employed informal caregivers (Schroeder, MacDonald, & Shamian, 2012), age-friendly communities (Menec et al., 2015) as well as service capacity and community integration (Kane & Cutler, 2015). These reviews highlighted informal caregivers' perspectives on the topic being reviewed. The search terms of informal caregivers, community and dementia within the EBSCO database generated an international collection of literature that ranged in focus from clinical studies on caregiver burden and education and psychological needs of caregivers, to definitions for social support and social networks, as well as the role of community in supporting informal caregivers. This literature was then reviewed with a focus on information provided by informal caregivers that defines the areas in which they need more support, what they would describe as effective support, how that support was provided and how the community could be involved in providing this support.

Caregiver's Definition of Support and Coping Strategies

One of the major themes found throughout the literature when looking at support, in general, is the importance of the caregiver being able to develop strong relationships with the care team of the person living with dementia. Members of care teams vary as the needs of people living with dementia and the needs of their informal caregivers also change. Informal supports may include extended family, neighbours, and churches (Chappell & Funk, 2011). Formal supports encompass financial institutions, health care professionals, paid personal care attendants, legal services, and housing supports (Chappell & Funk, 2011; Lopez-Hartmann et al., 2012). Informal caregivers of persons living with dementia identify being recognized as an equal partner in the care team as an essential component to feeling supported (Health Quality Council of Alberta, 2016; Holzhausen, 2015). Key elements of support identified by informal caregivers include acknowledging the expertise of the informal caregiver in their particular care situation, receiving consistent contact from others and the ability of the care team to be proactive in providing interventions and support (Daley, McCarron, Higgins, & McCallion, 2012; Gethin-Jones, 2014; HQCA, 2016; Holzhausen, 2015; Meyer, McCullough, & Berggren, 2016; Schroeder et al. 2011). Building on the foundation of trusting and consistent relationships, informal caregivers also spoke about the need to define the outcomes that are expected from their engagement with care teams and from the implementation of support strategies. They also requested that support address their own chronic health conditions, acknowledging that the use of humour relieves stress and it is important to focus on the positives in their lives (Boots, Wolfs, Verhey, Kempen, & de Vugt, 2015; Kuuppelomaki, Sasaki, Yamada, Asakawa, & Shimanouchi, 2004).

A consistent issue identified throughout the literature by caregivers is the need to ensure the diagnosis of dementia occurs as early as possible. This is identified as a key aspect in the informal caregiver's ability to adapt to the caregiver role (Boots et al., 2015; Han et al., 2014; Jowsey, McRae, Gillespie, Banfield, & Yen, 2013; Litzelman, Skinner, Gangnon, Nieto, Malecki, & Witt, 2015; Rutherford, Bowes, Mitchell, & Wu, 2014; Salin, Kaunonen, & Astedt-Kurki, 2009; Shahly et al., 2016). Garvelink et al. (2016) analyzed the effectiveness of interventions to improve informal caregivers' involvement in decision-making. They found a gap in support through decision-making processes, particularly at times of transition such as when an alternative level of care was being considered. The best approaches for addressing this and other caregiver needs was addressed in the research of Gallagher-Thompson et al. (2012). They concluded that "programs that involve patients and their families and are more intensive and modified to meet individual caregivers' needs seem to be the most successful" (p. 336). Their review looked at individual and family counselling, psychoeducational programs that teach caregivers skills to challenge pessimistic ideas about caregiving and reinforce the positive activities that are part of their role. They also looked at programs that teach caregivers how to modify their physical environment to promote independence of the person with dementia and how to respond and avoid problematic behavioural responses including managing sleep disturbance. Their review emphasized the need to address cultural beliefs about dementia and caregiving as well as the benefit of being able to offer multiple components of support to meet the needs of individual situations. They could not provide a definitive explanation as to why these programs had greater success but they suggested that it was because they were individualized to the informal caregiver's needs and that by providing a number of different approaches a variety of needs could be met. Lopez-Hartmann et al. (2012) and Sorensen et al. (2002) also found these best practices, like individualized plans, increased informal caregiver's ability to cope. The integration of supports for people living with dementia and their informal caregivers is seen as a crucial element to increasing caregivers' ability to cope (Lopez-Hartmann et al. 2012).

These multi-factored approaches allow greater flexibility in addressing the complex nature of the informal caregiver's role. The successful implementation of supports and interventions identified by informal caregivers increases their ability to manage their role and increases self-efficacy. For example, Zhang, Edwards, Yates, Li, and Guo (2013) define self-efficacy as referring "to a person's belief in their capability to accomplish a specific task when facing a variety of situations" (p. 1). They conducted a cross-sectional survey of informal caregivers in Shanghai, China using the Short-Form Health Survey, demographic data, dementia-related impairments, caregivers' social support, and self-efficacy in order to assess the role of informal caregiver's self-efficacy in the relationship between the informal caregiver's social support and their level of health-related quality of life. They concluded that an increase in self-efficacy decreases the informal caregiver's sense of burden and with greater social support their self-efficacy increases.

Informal caregivers also identified coping strategies that they found helpful and supportive to their sense of self-efficacy: ensuring they have structured breaks, adaptation of the physical environment, taking one day at a time, and accepting that no one is at fault are practical steps that informal caregivers are able to enact themselves (Johnson, Hofacker, Boyken, & Eisenstein, 2016; Kuuppelomaki et al., 2004). Outside help is generally needed to implement proactive problem-solving, increasing the understanding of dementia and the formal support system, and support to address stressors that are outside of their caregiving role including housing and legal matters (Johnson, et al., 2016; Kashiwagi, Tamiya, & Sandoval, 2016; Kuuppelomaki et al., 2004; Willems et al., 2016). Positive pre-morbid relationships, identification of the rewards of caregiving, and constructive coping styles are also strategies that informal caregivers saw as contributing to a sense of support (Shahly et al., 2012).

A small but significant area of research that contributes to informal caregiver's coping is the exploration of the positive aspects of caregiving. Informal caregivers of persons with and without dementia identified that due to their relationship with the care recipient they believe that they provide the best quality care for their loved one (Ratcliffe, Lester, Couzner, & Crotty, 2013; Vecchio, 2008). They also described their caregiving role as providing meaning and purpose in their lives and see it as a significant role that they perform for their families and community (Chappell, & Funk, 2011; Heo 2014; Ratcliffe et al., 2013). Heo (2014) identified the positive role that religious belief plays in supporting informal caregivers of persons living with dementia in finding meaning in their role and feeling connected to a community. In a Canadian survey of informal caregivers on the positive aspects of caregiving Cohen, Colantonio and Veronica (2002) found that recognition of positive aspects increases the informal caregiver's ability to cope and helps them to identify what specific supports are helpful in their particular situation.

A review of the literature on informal caregiver's perspective of social support identifies the specific and general elements that they feel support them in their complex and demanding role (Johnson et al., 2016; Takagi et al., 2013; Holzhausen, 2015; Schroeder et al., 2012; Gethin-Jones, 2014). Individualized approaches, recognition of expertise, adaptation to changing needs, recognition of the positive aspects of caregiving and the provision of social support are the general themes drawn from this review. Throughout the literature, the importance of social support is seen as a significant element in being able to access and implement the strategies that help caregivers cope (Chappell & Funk, 2011; Egdell, 2014; Rutherford et al., 2014; Schroeder et al., 2012;). Research looking at support networks and the factors that affect their impact will provide some insight into how they can be effective in providing support.

Factors that Affect Caregiver Coping

Informal caregivers are providing the majority of care to people living with dementia in the community (Alzheimer Society, Alberta and Northwest Territories, 2017). Lopez-Hartmann et al.'s (2011) systematic review of research on the effectiveness of the various types of support for informal caregivers identifies that there is very little research on informal caregivers and the research that does exist is often targeted at caring for those with specific chronic conditions. Informal caregivers often experience high levels of stress which impacts their emotional, psychological and physical health (Sorenson et al., 2002). They may be balancing work and their own chronic health issues while attempting to learn about dementia and approaches to care (Lopez-Hartmann et al., 2012; Shroeder et al., 2011; & Sorenson, et al., 2002). In their national survey of persons over the age of 85 years with functional disabilities in the United States, Takagi, Davey, and Wagner (2013) identify that being the sole caregiver and longer hours of caregiving are related to increased caregiver stress. Sorenson et al. (2002) reviewed the effectiveness of psychoeducational, supportive, respite-based, psychotherapy, care receiver-focused and multicomponent interventions on relieving informal caregiver stress. They identified that multicomponent interventions, a combination of psychoeducational, supportive, respite, and psychotherapy interventions that were tailored to individual caregivers had a greater impact than when a singular approach, such as psychotherapy, was employed. As dementia progresses the physical and emotional demands of the informal caregiver role also increases (Sorenson et al., 2002). This changing demand increases the complexity of accessing and establishing support for caregivers. Through their qualitative study, Daly, McCarron, Higgins, and McCallion (2012) developed the theory of “Living on the fringes” (p. 503) as the commonly experienced isolation of the caregiving role. This theory explains how informal caregivers of people living with dementia manage changes to their relationships within their social connections. Again Daly et al. (2012) found that isolation increases as the needs of the person living with dementia grows. The necessity of accessing social support is an essential aspect of a healthy caregiving situation.

The Membership and Roles of Support Networks

There is consistency within the literature of the membership and roles of support networks. Support networks develop from family, friends, service providers and community connections of informal caregivers and the person living with dementia. The social relationships that have been established prior to the diagnosis of dementia become the starting point of an individual’s support network (Egdell, 2012; Rutherford & Bowes, 2014). The range of members in personal support networks include family, friends, neighbours, work colleagues, formal services, service groups, religious communities, online communities and community organizations. There is usually a strong core membership within an effective network (Rutherford et al., 2014). The network supports informal caregiver's ability to plan for the future and meet the changing caregiving demands (Heo, 2014; Meyer et al., 2016; Nimrod, 2013; Rutherford & Bowes, 2014).

Support networks are uniquely positioned to assist informal caregivers to meet the needs that caregivers themselves have identified. Reduction of social isolation, assistance to access information and best practices related to dementia care, accompaniment to formal appointments, guidance through planning for the future and supporting caregivers at times of transition as care needs change for the person living with dementia are common roles for members of support networks (Daly et al., 2012; Egdell, 2012; Meyer et al., 2016). In an effort to understand how support networks grow to address these roles Egdell's (2012) qualitative research explored with informal caregivers how support networks develop. She identified three routes through which informal caregivers found support – guided, organic and chance. Each of these routes arose because of the circumstances of the caregiver. Guided development occurred when caregivers recognized that they needed more support and deliberately sought out network members. The organic route was used through a process of the caregiver and their network recognizing together that the demands of the caregiving role were increasing and greater support was needed. Finally, the chance route commonly occurred through crisis when outside help mobilized to address the situation and they then remained involved after the crisis. These routes affected the expectations upon the caregiver and the resources available to them. Stigma of the dementia diagnosis also impacts expectations and access to resources. Zelig's (2015) synthesis of cultural texts and findings from two studies of the use of the arts in working with people living with dementia both identify that the stigma associated with a dementia diagnosis is a significant barrier in the development of support networks. Those closest to a person with dementia may have the greatest difficulty recognizing the changes that indicate a possible dementia diagnosis. Friends and community supports may withdraw as the person living with dementia starts to express themselves differently through non-language based vocalization and physical activity that seems unrelated to their environment. A lack of knowledge and stereotypes regarding dementia can lead to an increase in the isolation of persons living with dementia and their informal caregiver (Egdell, 2012; Zeilig, 2015). Early diagnosis, proactive planning, communication to support network partners and openness to receiving support are key elements in maintaining and growing their networks (Egdell, 2012; Daly et al., 2013; Zeilig, 2015). The review of the literature on support networks identifies the needs of informal caregivers and what actions they can take to maximize the effectiveness of their support networks. These networks are able to assist informal caregivers to bridge the many aspects of care for a person living with dementia. Another approach to bolstering support networks is to examine the role of communities in sustaining the support networks of informal caregivers of persons living with dementia.

Community Support

Community can be conceptualized in many different ways, such as geographic location, a sense of belonging, common socio-economic circumstances and the opportunity to contribute and influence others (Crampton & Eley, 2013; Menec et al., 2015; Provencher, Keating, Warburton, & Roos, 2014; Roos, Kolbe, & Keating, 2014; Wen Li, Hodgetts, & Sonn, 2013). Wen Li et al. (2013) conducted interviews with older Chinese migrants to New Zealand through a family reunion program in an effort to explore their sense of community within multiple settings. The authors describe community as the "enactment of relationships between people, physical setting and social spaces" (p. 27). This definition allows for a flexible conception of community that has the capacity to create new relationships, to adapt the physical environment and to explore new concepts in an attempt to meet the needs of community members.

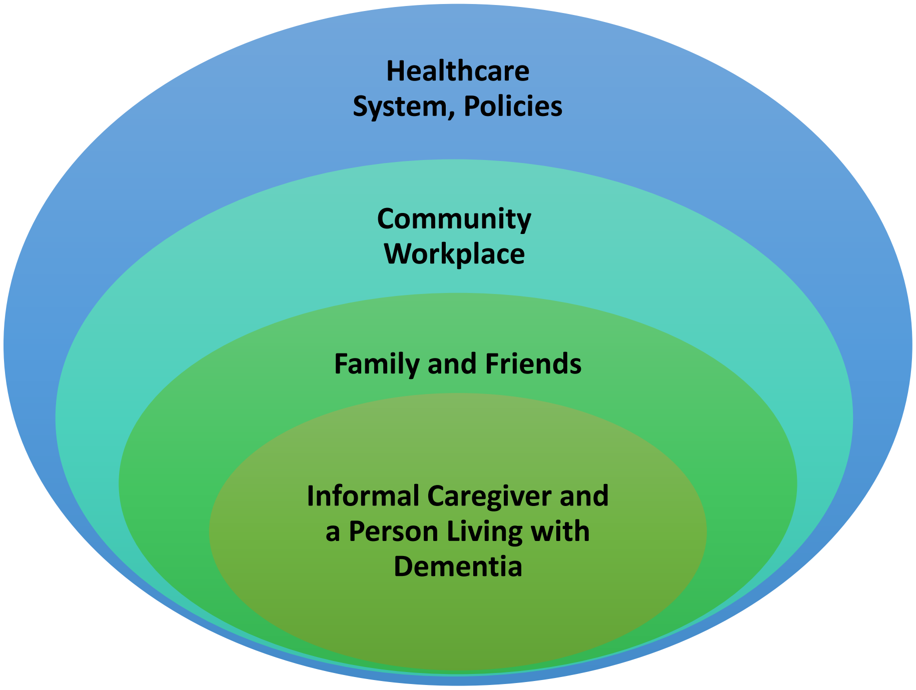
The involvement of community in providing social support is often discussed in the context of models of care within the literature (Kane & Cutler, 2015; Menec et al., 2015). Models described by health providers include the medical model, the chronic disease management model and the health promotion model. These focus on the diagnosis of disease and how to cure and manage the condition or how to maximize all aspects of healthy living to compensate for the diagnosis (Chappell & Funk, 2011; Keating and Eales, 2013). Recent developments in person-centred health care have begun to acknowledge the influence of relationships, social supports and community on an individual's health (HQCA, 2017). The supports that were identified by informal caregivers reflect a need for a broader approach.

There are a number of models within the literature that address specific aspects of care for persons living with dementia and the needs of informal caregivers. For example, Menec et al. (2015) review the influence of a communities' socio-economic status and the impact within rural versus urban settings on age-friendliness. The impact of a higher socio-economic level was seen as increasing the likelihood of infrastructure needs such as housing and transportation being in place whereas the proportion of older residents had the biggest influence on opportunities for involvement, social engagement and communication. In addition, Kerpershoek et al. (2016) use the Andersen Behavioural Model of Health Service Use to describe the factors that enable informal caregivers to access community services. Their model identifies predisposing and enabling factors that impact individual caregivers and acknowledge that the factors will change as dementia progresses. Kane and Cutler (2015) provide a conceptual framework for long term services that addresses the need for service provision to match the needs and preferences of the recipients. Their three-legged stool model situates environment, philosophy and service capacity as the foundational concepts in matching services to needs. Daly et al. (2012) developed the concept of "sustaining place" as essential in being able to provide informal caregivers the sense of appreciation of their role and in creating opportunities for both caregivers and persons living with dementia to contribute to citizenship. The World Health Organization (WHO, 2014) has promoted the concept of age-friendly communities, which includes dementia friendly. The tenets of this approach are to develop the opportunity within communities to have cross generational interactions, to develop a sense of belonging, encourage civic participation, adapt the physical environment to encourage accessibility and mobility for all, and an overall goal of obtaining a sense of well-being (Crampton & Eley, 2013; Keating & Eales, 2013; Provencher et al., 2014; Roos et al., 2014; Walsh, O'Shea, Scharf & Shucksmith, 2014; Wen Li et al., 2014; WHO, 2007).

The common themes among these five models are the recognition that providing support to informal caregivers is a complex process which is impacted by economic, social and emotional factors. These models convey that approaches are individualized to support informal caregivers and that there is flexibility to be able to change what is provided as the needs of the caregiver change. As well, the opportunity for the informal caregiver to see meaning in their role and to have a sense of their contribution is an essential element of these models. The vision of the WHO (2014) age-friendly community encompasses the ideals of all of these models. The ability to implement this vision requires the collaboration of business, government, religious groups, senior centres and community groups. Communities will be challenged to address education, awareness raising, environmental changes and relationship building as part of this implementation.

These previously described models address individual aspects of the caregiver role. Urie Bronfenbrenner (1979) developed the ecological systems model to bring together these aspects of the multiple layers in human interactions. This model has been used as the foundation for many subsequent approaches in understanding the relationships between individuals, communities and the broader society (Egan & Cowan, 1979). This model is particularly useful in the context of support networks because it outlines four layers of interactions which impact all relationships and affect the caregiver's sense of support (see Figure 1). At the centre is the informal caregiver and the person living with dementia. The first layer beyond the centre is the network of personal settings, or the people with whom we have the closest relationships like family and friends. This relates to the family and close friends of informal caregivers of persons living with dementia and their ability to provide support. The second layer is the interactions between the members within our personal settings. These linkages may provide support or stress and sometimes both. Support networks provide the linkages within this layer. The third layer is comprised of the community including the workplace. This layer often provides opportunities for involvement in activities and it also encompasses the community services which may have the capacity to provide direct support and assistance in developing support networks. The final layer is culture which encompasses language, norms, values and laws. The larger culture of our society shapes institutions and determines the laws and rules by which we live. This layer lays the foundation for the development of policies that support informal caregivers. It includes the larger institutions of health, legal, economics, education, media, and religion. This model expands our understanding of the complexity of the influences on how we make decisions, our ability to build relationships and how we interact with our communities. It maps the connection from the individual support needs of informal caregivers through to the policies that influence the provision of those supports.

Figure 1: Ecological Model (Adapted from Bronfenbrenner, 1979)



A new area of development for communities in the third layer is to understand their role in developing and sustaining support networks for informal caregivers of persons living with dementia. Support for communities to meet these challenges is also needed from a societal approach in the form of policy development.

The Role of Policy Development

Within the Canadian context, the focus of policies related to informal caregivers of persons living with dementia is the provision of Home Care, financial support through pensions, financial support through income supplements and employment insurance for end of life care (Canadian Policy Research Networks Inc., 2005; Cool, 2012). Robin Stadnyk (2009) provided a comprehensive analysis of public policies that impact informal caregivers and the costs incurred by informal caregivers in Nova Scotia and Alberta. This analysis identified policies within these sectors: health, income support, labor and employment, transportation and housing, and non-profit organizations. The supports described in this analysis are a patchwork of policies which require a significant investment of time to understand and access. Four themes are identified in this study (Stadnyk, 2009). The first theme describes the location of the caregiver, either in the same region versus further away, and how this affects the eligibility of the caregiver to receive certain supports. This includes home adaptation grants for the informal caregiver's home if they did not live in the same region. The second theme is the balance that informal caregivers often have to assess to ensure the positive aspect of policies are commensurate with the cost that accompanies it. The common example was the provision of respite services in a day program or facility. While this provided relief to the informal caregiver, there was a charge for this service. The third theme states that most benefits provided to informal caregivers are tax-based and therefore favour those who are employed. The Federal Caregiver Benefit and leave of absence benefits through Employment Insurance are two examples of tax-based supports (Stadnyk, 2009; Schroeder et al., 2012). The final theme in Stadnyk's (2009) analysis outlines that employed caregivers often are deciding that in order to provide care they must limit their career opportunities through turning down advancement opportunities, reducing work hours and limiting their involvement in work related projects (Stadnyk, 2009; Schroeder et al., 2012). These decisions impact their present-day finances and the longer term economic situation of themselves and their families (Stadnyk, 2009; Schroeder et al., 2012). The complexity of the matrix of these policy areas affecting informal caregivers is also identified as a challenge in conducting the analysis and in informal caregivers being able to identify supports and navigate the processes to access them.

In the literature, many aspects of Canadian society are identified as being impacted by the funding processes and availability of formal care supports. These include the ability of the labor force to arrange flexible work conditions, gender bias towards an expectation that women will be providing care, individual choice in becoming a caregiver, and the differences in the type of and access to supports in rural and urban communities (Broese van Groenou & Boer, 2016; Chappell et al., 2011; Keating & Eales 2013; Shroeder et al., 2011). Through the review of informal caregiver's view of effective support, it is evident that the caregiving role is complex. It requires caregivers to be flexible and adaptable to the changing needs of the person living with dementia. Supports need to be able to respond to this progression of needs and to ensure that informal caregivers feel empowered in their role through the provision of dementia related education, respite care, psychological and emotional supports as well as the development of effective support networks (Gallagher-Thompson et al., 2012; Lopez-Hartmann et al., 2012).

There are several areas in the literature identified as benefitting from future policy development to provide direction in meeting these needs. Policy is needed to ensure caregivers are supported with a timely response of supports and that informal caregivers are the ones directing support including financial benefits (Barnes, 1997; Crampton, 2013; Kane & Cutler, 2015; Torjman, 2015). Public education and policies that strive to normalize the responses and support needed for persons living with dementia is identified as part of the effort of reducing the stigmatization and isolation that informal caregivers experience (Barnes, 1997; Crampton, 2013; Ratcliffe, 2013).

In Schroeder et al.'s (2012) overview of demographic and policy trends and potential policy responses, they outline the impacts of providing care on informal caregivers who are also employed full or part time. They identify that within the Canadian context there is limited federal government support through the Compassionate Care Benefit and the Caregiver Tax Benefit. Individual businesses have implemented human resource strategies which support informal caregivers but these are not widespread practices. Schroeder et al. (2012) further identify that the work environment can be a critical source of support. Workplaces that allow for flexible schedules provide benefits that provide coverage for caregiving activities and recognize the long-term benefits of retaining an experienced employee are a significant aspect of an informal caregivers' support network.

The importance of empowering informal caregivers in their role signals the role of policy in ensuring informal caregivers have access to education related to dementia and the caregiving role, and the most recent research in the care of persons with dementia (Auer, 2014; Barnes, 1997; Samia, 2014). Another strong theme in the pursuit of empowering informal caregivers is the development of policy supporting direct funding for care (Barnes, 1997; Kane & Cutler, 2015).

Broese van Groenou (2016) identifies direct funding as impacting who will be able to be a caregiver. Barnes (1997) outlines that direct funding will change the relationship between informal caregivers and formal supports by recognizing the expertise of the informal caregiver and encouraging collaboration. Increased collaboration across support networks will enhance the development of person-centered care. The reduction in the existing overemphasis on safety and bias towards institutional care and an increase in modifying the environments of persons living with dementia will support the provision of care at home (Daly, 2012; Kane & Cutler, 2015). There is fertile ground for developing innovative policies that target resources at the individual and community level so that a strong infrastructure to support informal caregivers through their support networks can be developed.

Summary

This review of the literature of informal caregivers' perspectives on the factors that impact caregiver's ability to cope and their sense of what is meaningful support has described consistent themes. Informal caregivers expressed the need to have their work recognized as complex and rewarding. The progressive nature of dementia requires flexibility and a recognition of the multiple transitions in the care journey. Supports need to provide a range of options, which can be individualized to the particular situation and adapt to these changing needs. Support networks are a key component to assisting informal caregivers to access education, formal supports, social interaction and maintain a connection to their broader community. Further exploration of the factors that support the development of effective support networks, as well as the role of communities and policy development in supporting networks to develop and grow into the future is needed.

The community's capacity to recognize the contribution of informal caregivers creates opportunities for the caregiver and the person living with dementia to participate in their community. Communities can also provide support to networks in an effort to contribute to an inclusive, supportive experience for everyone. The alignment of these three layers of support has the potential to build resilience for both informal caregivers and communities.

Chapter 3: Methodology

Introduction

The insights and knowledge of informal caregivers of people living with dementia were gathered to answer the question: what is the role of support networks in the lives of informal caregivers of people living with dementia? Two sub questions helped to explore this question further: how do informal caregivers see support, and what factors influence the role of support networks of informal caregivers of people living with dementia? I used a qualitative descriptive methodology which is “committed to studying a phenomenon in its natural state” (Sandelowski, 2000, p.337) to describe it as though it is not being observed. Qualitative descriptive methodology draws on the naturalistic experience of participants through interpretation and induction. This methodology tries to interpret the meaning that people give to their experiences (Mayan, 2009). The description of a phenomenon through a qualitative descriptive approach allows for elements and characteristics to emerge from first-hand experiences. This chapter details the processes that I used to conduct this research.

Participant Recruitment

Purposeful selection was used to recruit participants who were informal caregivers of people living with dementia residing in the community. They were recruited through a request for participants made at my church by providing a short public announcement during a Sunday service and placing an announcement in the church’s weekly newsletter for three consecutive weeks. Five participants were recruited through this approach. Of these five participants, three were referred by a church member and two self-identified themselves. In addition, one participant was recruited through the Alzheimer’s Society of Alberta and Northwest Territories.

They shared information about this study to caregivers of people living with dementia at their main office.

Ethics Approval

Ethics approval was obtained from the University of Alberta Research Ethics Board, in the branch of Human Research, board one.

Informed consent (Appendix C) was obtained from all participants through discussions with them and signed documents. During the first telephone conversation to arrange the first interview I provided an overview of the research project. I also told the participants that they could stop the interview at any time. At the start of the actual audio-recording for both the first and second face to face interview, this information was reviewed again. Interviewees all knew they were committing to participating in two interviews. The consent form was reviewed in detail and signed at the initial interview.

Data Collection

Data collection took place by conducting individual interviews with six participants on two separate occasions. Both sets of interviews were semi-structured. At both sets of interviews four questions were asked: Who is part of your support network? What roles do they play in your life? What does support mean to you? How do your support networks contribute to your feelings of support? Additional probing questions were asked to clarify and expand on the expressed ideas.

The second interview asked the 4 initial questions again as well as further probing questions. These interviews were conducted to allow the opportunity for caregivers to clarify and build on ideas from the first interview, dive deeper into their ideas, discuss new ideas and provide richer descriptions. Overall, this produced a collection of ideas from twelve interviews that were analyzed by looking for similarities and differences.

Of the twelve interviews, ten of them were conducted in the participant's home and two were at a coffee shop. The interviews were audio-recorded with the consent of the interviewee. After conducting three of the initial interviews, I transcribed the audio-recordings verbatim. I transcribed the interviews by speaking the words of the interviewee and interviewer into a Google microphone-enabled document which typed the spoken words onto a document. I listened to the audio-recordings while speaking the text. After approximately two to three paragraphs the verbal typing was paused and I listened to the recording again and manually corrected any discrepancies in the transcription ensuring they were accurate. All interviews were transcribed in this manner.

Research memos were used throughout the data collection process. Memos were handwritten following each interview, during the transcription of the interviews and following the transcription process. These memos included significant ideas shared by the caregiver, such as how caregivers described themselves, the situation of the caregiver (e.g., one caregiver had been sick the night before both interviews), points repeated by the caregiver, how the second interview related to the first one, my impressions of how the interview had gone and what impact I may have had on the interview.

Data Analysis

I employed an iterative approach to the data analysis. Conducting two sets of interviews with each participant and writing the research memos at a variety of stages of data collection supported the collection of credible data. The ongoing comparison of data between participants, across the first and second interview and between the transcriptions and the research memos was the basis of this credibility. The use of two sets of interviews with each caregiver and the purposeful selection of participants with lived experience as an informal caregiver who lives with and cares for a person with dementia developed the confirmability of the data. The approach to the collection of data across the two interviews and using written observations in the research memos, as well as the purposeful selection of participants supported the development of dependable data. Reflexivity was an important aspect of collecting this qualitative data. I reflected on personal biases and previous knowledge and opinions that I brought to this project by using the research memos and during the review of my data collection and data analysis process with my supervisor.

The research memos explored ideas the caregivers expressed repeatedly and emphasized as significant, assumptions that I realized I had going into the interviews, the health of the caregivers as well as ideas that were supported or not by the literature.

Once an interview was completed and transcribed, I created a detailed compilation for each by reading through each transcription three times. The detailed compilation listed factors that influenced support, how caregivers described support, a profile of the caregiver and key quotes from the interview. Aspects of the research memos were incorporated into the detailed compilation as well.

Once the detailed compilations were completed for each interview the data was grouped into roles described by the caregivers. Similarities and differences in who performed these roles were noted. The identified roles were reviewed for factors that influenced the identified roles and how caregivers described feeling supported. Similarities and differences were noted in these factors and their description of feeling supported. The major roles emerged from this analysis. Table 1 below provides an overview of the data analysis process.

Table 1 – Data Analysis Stages

Stage in Data Analysis	Activities
1) Interview # 1(N=6)	-Transcription -Research memos -Identifying common ideas across all six interviews
2) Interview # 2 (N=6)	-Transcription -Research memos
3) Read 12 interviews three times	-Highlighted comments related to the role of support networks in the lives of informal caregivers of people living with dementia
4) Developed a detailed compilation of 12 interviews	-Caregivers description of how they saw support -Factors that influenced support networks -Profile of caregiver -Key quotes relevant to the main research question and the two sub questions -Integration of research memos
5) Identification and description of major roles	-Roles of support networks identified

The qualitative descriptive methodology used within this research generated rich data that facilitated the ability to discern the complex nature of support networks for caregivers caring for people with dementia. The methodology captured the voices of informal caregivers about the role of support networks in the lives of informal caregivers of people living with dementia.

Chapter 4: Findings

The findings presented here address the research question: what is the role of support networks in the lives of informal caregivers of people living with dementia? The findings also address two sub questions: how do caregivers see support? What factors influence the role of support networks?

The organization of this chapter starts with a description of the context for the findings and then reviews the five major roles that emerged from the data.

Context for Findings

The five major roles of the findings are better understood with a description of the membership, setting and influences on informal caregivers' support networks. This section provides a description of the research participants, who they view as members of their support network, how caregivers view support, and what factors they see as influencing the role of their support networks.

Study Participants.

The participants were all informal caregivers living with the person with dementia and residing in the community. Of the six participants, four of them were wives of the person living with dementia, one a husband, and one a daughter. Their ages ranged from fifty-three to ninety-one and the ages of the people with dementia were from age seventy-three to eighty-nine. The caregivers had been providing care for three to ten years and two of them were still working while the others were full time caregivers. Three of the caregivers participated in formal support groups for caregivers of people with dementia on an ongoing basis, two had attended a few sessions and not gone back, and one was not interested in attending. The support groups were organized by the Alzheimers' Society of Alberta and the Northwest Territories.

Who are the Members of the Caregivers' Support Networks?

When asked to describe their own support network the caregivers consistently identified four key members of their support networks: 1) family, 2) friends/community, 3) healthcare providers, and 4) formal support groups. They provided descriptions of moments when these members were supportive as well as when they experienced negative impacts or when they were absent. One caregiver spoke about support from family this way:

> Yes I have a daughter that has power of attorney….that helps a lot and
> she does support greatly, and she seems to be able to have time to take off when
> it is necessary….lets' see it has been going on ten years.

Another spoke of family and friends support:

> My quote/unquote support network would be my [family member]
> although he is not supportive at all, then when the one [friend] who is my
> support network says she does not want to hear it [about unsupportive family
> member] anymore…..she's just tired of hearing about it.

One caregiver described the support that she receives from her community group, "my Tai Chi group is a great support group, a couple of them understand, they speak to my [family member], they keep him involved."

Alternatively, another caregiver spoke about the effect of absence of friends:

> I have friends and I know they have lots of other things going on
> but they either don't want to hear it or they don't reach out to me.
> I have to reach out all the time which is exhausting.

Healthcare providers as support network members were described this way by another caregiver:

> There's been some very good people working in home care and our

> current nurse, Alberta Health Care case manager who started with us right after his stroke really understood. The other case managers looked at me like I was expecting too much for [person living with dementia].

The caregiver's description of the members of their support network reflect a range of positive and negative relationships and show how these relationships impact how caregivers see support. The next section outlines the caregivers' reflections on how they see support.

How do Caregivers See Support?

When caregivers answered the sub question of how they see support they described four main characteristics: 1) support needs to come from all levels; 2) when help was offered without the caregiver asking, it had a big impact on feeling supported; 3) when others understood dementia and had skills in interacting with the person with dementia it helped significantly in being supported; and 4) network member's assistance in accessing and implementing resources, such as a GPS tracker, was important.

Caregivers described the need for support to be at all levels for them to feel that they are being supported. They described 'all levels' as those closest to them being on one level and family and friends being the next level. Another level was support from the community and a final level was described as support from government and society in general. One caregiver spoke about these levels when she said, "I think that people don't know the magnitude of the role that dementia plays, how many people it affects beyond the people with the diagnosis including the caregivers."

Another caregiver described the different levels of support that she receives from her doctor:

> He is able to observe me and observe [family member] and comprehend the situation and take action at multiple levels to

> coordinate services so I don't have to, [I] experience being seen, taken care of so that I don't have to keep advocating or become strident about what I'm doing.

Throughout the interviews caregivers said that when one area of their support network was not supportive it meant that they had to increase their time and energy to address this gap. One caregiver describes it this way:

> My son lives [away from her] and tries to help over the telephone…it is some of those practical things, like take things back to the store, into the bottle bin or any of those kind of chores, did anybody mention how time-consuming all of this is, it seems like I don't have enough time for anything because I have to take care of all these little problems…..and then it eats into your own time, when you should be taking care of yourself.

These examples provide an understanding of how support at all levels contributes to how caregivers see support.

The second area that caregivers identified as contributing to how they see support is when network members offered help without being asked. Caregivers did not expect this to occur but described the relief and support this provided them. One caregiver described this type of support from her privately paid caregiver this way:

> When [private, professional caregiver] comes here he takes over, I don't have to show him what to do, this is one of the things I really like. And I ask him, okay, what are your plans for the day and he says well I think we will do this.

Another caregiver said:

> My neighbors are quite supportive for talking to and helping with a few things like if something is wrong with the car. [Friend] with the Tai Chi group …..she takes me to her choir's concerts, drives me there also.

This active outreach to caregivers contributed to their sense of being supported. The third area that caregivers identified as contributing to their sense of support was having network members with pre-existing knowledge of dementia so they knew how to interact with the person living with dementia. A caregiver described it as "trying to make sure that when I'm not there that quality care is there, so even when we have respite I want to make sure that the people who are helping are actually engaging with [family member]." When describing what it meant to have good quality care another caregiver said "I can actually turn my mind off for this little bit of time and concentrate on what I want to." Caregivers described that when they did not have to educate a network member about dementia it contributed to feeling supported.

The fourth and final characteristic that caregivers discussed about how they see support is when they receive practical help to access and implement resources. This included such things as snow shoveling services, discussing what care facilities were the best, and how to buy and set up a GPS tracking device. One caregiver described her experience when she said "There's so much to be thinking about. You feel like you have to be on top of it and the information is scattered all over. You can't take it in all at once."

These aspects of how caregivers see support help to set the context of the main research question: what is the role of support networks in the lives of informal caregivers of people living with dementia?

What Factors Influence the Role of Support Networks?

In addition to how caregivers see support, the context for the findings is clarified further when the caregivers described the factors that influence the role of their support networks. Caregivers identified four influencing factors: 1) the loss of the core member of their network to the diagnosis of dementia; 2) the worry of caregivers that they are increasing the burden on their family when they ask for help; 3) the withdrawal of the community from their network; and 4) how their personal philosophies about caregiving influenced their sense of support. These factors influence the role of the caregiver's support network.

The first factor influencing the role of the support network is the loss of the caregiver's core member to a dementia diagnosis. Caregivers described this loss as significant and a factor which they experience on an ongoing basis. One caregiver said "I think that's one of the hardest things for me is that my [family member] was always my primary support and so I feel like I've lost my best friend and I have really." Another caregiver said, "because you are looking for your soul mate, your partner in life if your married and you don't have that anymore…it's really tough at times." This loss was expressed by all the caregivers and they described it as impacting them on an emotional and practical level. Another caregiver said that "If he wasn't so far gone he could help me, my source of information is gone, so with everything I have to do [it] myself."

This loss of the main support person in the informal caregiver's network to the diagnosis of dementia, is also a loss for all members of the network. The person living with dementia is gradually unable to maintain the many roles they played as a father, mother, friend, or sister, reducing the support they can give to others. All members of the network have to adapt to this change and caregivers described this as a burden on their family.

The second factor that caregivers identified as influencing the role of their support network is that caregivers worry that they are being a burden on their family supports. One caregiver described his worry about the burden on his family by stating "But I know I can't drain them too much, [family member) has had her own problems, um not her problems but her mother in law just passed away." Another caregiver said, "And you know where family members are concerned they have their own difficulties and you don't want to burden them but sometimes they pick up the vibes." The caregivers' descriptions of being mindful of the stress they put on their families showed that this influenced how much they asked their families to do and how often they asked for help.

The third factor that caregivers identified as influencing the role of their support networks was their communities withdrawing from their lives. The caregivers described friends no longer calling them or being asked to stop their participation in activities as their loved one's diagnosis of dementia became more apparent. Places and groups that they had once felt they belonged no longer welcomed them. One caregiver described this loss when she said, "I mean I used to reach out to a lot of different people but I just stopped, they just stopped responding so I decided I'm not doing that anymore, so it's a huge watershed with social relationships." Another caregiver described the withdrawal of their community as a loss when she described her family member's network "That is a sad thing, my [family member] had a very broad social network, she was engaged in a lot of activities and a lot of things, and as her memory got worse people cut her off."

The withdrawal of the community was described as a loss of meaningful interaction for the person with dementia as well as a loss of social interaction for the caregiver. Friends and communities that had a shared history with the caregiver and person with dementia were no longer part of their lives. While all the caregivers described some loss of community, in the instances where community involvement was still present it greatly enhanced the support the caregiver felt. This caregiver described his ongoing volunteer job as being a big support:

> Working over at the museum…..it is lots of room to walk around there and so I felt that this is very supportive…..oh yes, there are also visitors as well as help, but she has coped with that fairly well, it is kinda annoying at times when she breaks in with some funny sayings but that is understandable and most groups that are introduced are notified of that [her dementia] when she is there….. Well it [working at the museum] has been keeping me going, gives me something to look forward to.

Another caregiver described her Tai Chi group this same way:

> The Tai Chi group and a whole bunch of ladies there, they're very nice to us, that's very important to me. I think they're both 15 years younger than the rest of us. We've been doing Tai Chi for quite a few years. The [family member] can still do some of it as long as he's in the middle, he can follow.

Caregivers' description of the influence of the community on their sense of support contributes to understanding the role of support networks in caregiver's lives.

The fourth factor that influences the role of support networks on informal caregivers was expressed by only two of the caregivers but they felt it was significant to their sense of support. They described their philosophy about caregiving as contributing to their sense of support. One caregiver described her approach when she said, "But the best lesson learned is that you have to take every day for the best, but it can be for whoever appreciates it and makes the most of the day can bring." She described this attitude as contributing to her ability to manage her stress and feel supported. Another caregiver described that part of her upbringing was to value being part of a caring community. As a child she lived close to a mental health care facility and she knew that if she met someone who was confused and distressed that she needed to help. She described this sense of caring for everyone in her community as building a foundation for her caregiving role.

The findings that arose from the caregiver’s responses to the two sub questions of how caregiver’s see support and the factors that influence the role of support networks offers a description of the context for the major roles of this research. This context outlines the complexity of being a caregiver for a person with dementia and the many players that are part of their support network. As well, it contributes to an understanding of the major roles of this research. These major roles are discussed in the next section.

Major Roles

From my twelve interviews with six informal caregivers of people living with dementia, the data can be described in the form of five major roles. The five major roles addressing the question of the role of support networks in the lives of informal caregivers of people living with dementia role are: 1) to participate in advocacy to address the stigma of a dementia diagnosis; 2) to understand and help others understand dementia; 3) to assist in accessing and coordinating resources; 4) to provide care to the person with dementia; and 5) to help to coordinate support at all levels.

Addressing the Stigma of Dementia.

Caregivers expressed the ongoing need to fight against the stigma of a dementia diagnosis. They spoke of the doctor’s resistance to test for dementia because of the stigma. One caregiver described her daughter’s role in the process of receiving a diagnosis for her husband:

> Well it is interesting, for quite some time before it was recognized by his doctor, who I always thought of as a loopy guy, he would go to the doctor and

> [he was told everything was fine], anyways, finally I said I am going to go with you. Well the doctor listened to me and thought I was loopy. So I said okay, I will get my social worker daughter, so she came and as soon as she came and talked to him, he listened. So then he did the mini-mental and all those things and then said "oh yeah I think we have a problem". It went undiagnosed for at least three years.

Another caregiver described the effect of the stigma associated with dementia on her friends when she said "I think people are scared, they probably know somebody with dementia but they're scared, they just don't want to think about it. [They are afraid of] getting it themselves or somebody close to them getting it."

This caregiver talks about the stigma she encountered while grocery shopping:

> When we get to the till [I say] now hold on to the cart, some of the people look at me funny but then not very many of them have ever asked me and unless they ask I don't volunteer.

Addressing stigma requires the need to participate in advocacy. Advocating for the person with dementia to receive appropriate treatment was described this way by one caregiver:

> Every time, if there's a crisis I'm the one that has to figure it out, how to navigate for him because in the [health] system there is a triage and after a certain age there are judgements made about the worth of that particular person and that's why I say some specialists are not really interested in having customers that are complicated, they're not part of the caring system.

In this study caregivers expressed the need for support in participating as an advocate in addressing the stigma associated with dementia. They said it was exhausting and took away from the day to day care of the person living with dementia. Closely related to the need to address stigma, caregivers identified that they needed support network members who understood dementia and could pass along this knowledge. Knowledge and information about dementia was seen by the caregivers as one strategy to combat the stigma.

When caregivers interacted with network members who already understood dementia and could also interact with the person with dementia in a meaningful way they described feeling validated and supported. One caregiver described the role of her daughter in providing this support when she stated “When I am at my wits end I will call her up and say “what should I be doing”, well anyway she sort of gets me back on track.”

Understanding Dementia.

Another role of support networks in the lives of informal caregivers of people with dementia is to understand and help others to understand dementia. Descriptions of the effect of a lack of understanding of dementia, however, was a common experience for caregivers. This caregiver describes her experience at the emergency room:

> One of the things that did happen when I took my mom to emergency, the doctor said because she had dementia you [the doctor] can’t believe what she says, you have to go by physical characteristics. Okay, you [the doctor] talked to her for a whole half of an hour and [the doctor] automatically label[ed] her with a dementia and [the doctor] says that she can’t respond, I don’t believe that to be true.

In this case, the doctor’s lack of knowledge of the different stages of dementia meant that the caregiver had to advocate for her family member to have a voice with the health professionals.

Another caregiver speaks about her efforts to have the health professionals understand her family member's dementia:

> Because of the models in medicine these days they ask the patient 'what do you need' which doesn't work when someone doesn't understand that [the patient] has any form of dementia, it's like asking a child in a medical interview what do you need, so it's been beyond stressful. I thought the whole medical [system] has not been supportive…..I found it never really was brought together here in Edmonton, although our new GP got the picture but it took a lot of work, and I had to go in with two pages all typed out……Once I didn't have to keep establishing my credibility or come in with a checklist of observation [I felt supported].

Caregivers also described the social isolation that occurs when community groups are not knowledgeable about dementia. This caregiver provided this example:

> My [family member] loves to play bridge but all her friends who played bridge booted her out and told her she wasn't welcome, so I found [another group] and it was horrible. They said they were a social bridge group and so I took her and dropped her off…..I went and picked her up and this man was yelling at her.

Another caregiver describes what she needed from a qualified health care aide who understands dementia when she said "I need someone who will interact with [partner with dementia], to ask him what he's reading and what would he like for supper."

The role of understanding dementia and developing skills in interacting with the person with dementia is identified by caregivers as an area that all members of their support networks need to acquire. Caregivers describe that the time they spend in educating others about dementia is significant and contributes to feeling overwhelmed in their caregiving role. Understanding dementia also enhances the ability to address the next major role of accessing and coordinating information.

Accessing and Coordinating Resources.

The third major role that addresses the question of the role of support networks is the very practical intervention of assisting in accessing and coordinating resources. The resources that caregivers of a person with dementia need are continually changing with the progression of the disease. This constant change is caused by both the changing needs of the person with dementia and their decreasing ability to carry out their family roles such as their ability to drive, manage finances, or cook. These are examples of new roles that caregivers come to assume to manage the household. In addition, the person with dementia may have additional needs. Some examples from the caregivers include needing a tracking device as a safeguard if the person with dementia wanders, management of other chronic conditions and finding meaningful activities for the person with dementia. One caregiver described the overwhelming nature of accessing and coordinating resources when she said "There's so much to be thinking about. You feel like you have to be on top of it and the information is scattered all over. You can't take it in all at once."
Caregivers did describe the usefulness of attending formal support groups to access information. One caregiver said this:

> Who is part of my support network? Definitely the Alzheimer's Society. I actually think that was one of the best things I did, was going to their Care Partners networking sessions…..Understanding that there were other people in the same situations.... one of the things he said to me was to go

> get all the legal documents sorted out and that was good advice….then also for getting resources there.

Caregivers identified that they need help in finding resources from all network members and that they also need help in instrumental activities. An example given by one caregiver was needing help to understand a GPS tracker, knowing where to order it, and then being shown how to operate it. Previously this help would have been provided by the person living with dementia. As well, since the person with dementia is no longer able to do the household activities, caregivers often described needing increased assistance to do these activities. At the same time that there is an increased need for assistance in accessing and coordinating resources, the need for care of the person living with dementia is also increasing. The fourth major role will look at the role of support networks in the provision of care.

Care Provision.

Providing care for the person with dementia can take different forms. Caregivers described the ongoing involvement of the person with dementia in activities, like the Tai Chi group, as one way care is provided. They also described the value of their family coming to stay and the caregiver being able to leave for a while as caring. Formal care was described by caregivers as being provided through day programs, or by health care aides in the home or by providing respite in care facilities. As described in the second role, the role of support networks to help others understand dementia, caregivers repeatedly spoke of the need for high quality care to be provided by all network members. One caregiver described exchanging care with a friend who was also a caregiver when he said “We get together with [friends] every once and awhile. We haven’t exchanged babysitting yet, but I have been kind of wondering if we could arrange that.”

Caregivers identified this need for the provision of care as a key element in their ability to remain involved in activities that were meaningful for themselves such as work, social groups, volunteer work and exercise. A caregiver spoke of the importance of maintaining her work life when she said "I've had to cut back on my practice which isn't just money making, it's also a place where I'm creative and also if I wasn't doing this [work] I would be called to do almost everything." This caregiver speaks to the ongoing expectation that as the needs of the person with dementia increase then the primary caregiver continues to address these needs while maintaining their other roles like work or child care. This was expressed by all the caregivers.

Coordination of Support at All Levels.

The final role that arose from the twelve interviews with informal caregivers of people living with dementia, incorporates all the major roles in the coordination of support at all levels. These levels include family and friends, community, service providers, societal values and policy. Throughout the description of the first four major roles the necessity for all support network members to be involved in meeting the needs of each major role was described. When one member of the network was either negative or absent caregivers described the huge impact on their sense of being supported. This fifth role is about the support network members organizing to coordinate support in all the roles at all levels. The levels were described as personal contacts of family and friends, next the broader community service providers and then societal values and then the policy level. Caregivers identified that without this coordination their sense of support would be minimal. One caregiver said that he has good support from family, friends, and their doctor but he receives minimal support from formal in-home services and support groups. This caregiver was reluctant to attend the formal support groups for caregivers at the Alzheimer's Society because he felt they asked questions that were too personal. He had also been unsure about having health care aides provided through home care because the staff changed too often. These gaps limited the amount of support he experienced and he was not sure how to have them addressed.

Each caregiver described gaps within their support networks. Some of the caregivers could see the gaps but often did not have the energy to address them or did not know how to address them. One caregiver accessed both in home health care aide support and an adult day program for her loved one with dementia, she had good support from her Tai Chi group and neighbors but she had difficulty accessing the family doctor, she was not comfortable going to the formal support group and her only family lived in Vancouver. She identified that she felt frustrated trying to access practical help around driving and doing chores, she felt overwhelmed by the number of chores and she did not have support to think about the next level of support that her family member may need. These two examples illustrate that each caregiver have unique situations but it is the coordination of these resources that would ensure there is overall support which they both saw as being able to increase their sense of support.

Summary

The context of the findings adds to the understanding of each major role by describing the members of the support networks, how caregivers see support and how they describe the factors that influence support. The five major roles addressed the question of the role of support networks in the lives of informal caregivers of people living with dementia. The following Discussion and Conclusions chapter will further explore the major roles as to how they reflect and add to the existing literature, and the implications for support networks for informal caregivers of people living with dementia.

Chapter 5: Discussion and Conclusions

This chapter is grounded in the research question: what is the role of support networks in the lives of informal caregivers of people living with dementia? Insights generated from the two sub questions: how do caregivers see support? and what factors influence the role of support networks will also inform the chapter. These two sub questions provided the context of the research. Also, grounding this Chapter is the literature found in Chapter 2. Another source upon which this chapter is grounded are the observations in my Research Memos. Finally, this Chapter discusses the implications these findings have for the role of support networks in the lives of informal caregivers of people living with dementia.

In response to the first sub question: how do caregivers see support, caregivers described four characteristics. These characteristics are: support being offered without the caregiver asking for help; the network members understanding dementia; network members assisting with accessing and implementing resources; and having support at all levels, which includes close family and friends, the community and societal values and policies. The second sub question asked: what factors influence the role of support networks? Caregivers identified these to be: the loss of their core support network member to a dementia diagnosis; their concern of burdening their own family; the withdrawal of their community; and their own values and perspectives on caregiving.

Through this research informal caregivers of people living with dementia shared their experiences and perspectives. In the literature, their perspectives are discussed but indirectly, that is, the focus is on the effectiveness of interventions on caregiver's skills to provide personal care, learn new communication strategies and respond to expressions of agitation by the person living with dementia (Gallagher-Thompson et al., 2012; Lopez-Hartmann et al., 2012; & Zhang et al., 2014). This has left a gap in the literature. We do not know the role of support networks as described by informal caregivers themselves. The description by caregivers of the context of their situation assists in understanding the major roles in this research.

This chapter provides a discussion, through integration with the literature, of the five major roles that address the role of support networks for informal caregivers of people living with dementia. The major roles are: 1) to participate in advocacy to combat stigma of the dementia diagnosis; 2) to understand and help others understand dementia; 3) to assist in accessing and coordinating resources; 4) to provide care to the person with dementia; and 5) to help to coordinate support at all levels. The discussion brings new understanding about the support networks of these informal caregivers. Two key insights can be drawn from this study. First, there is a recognition that the support of the community is a key element in informal caregivers' sense of support but the community has often withdrawn and is absent as part of the support network. Second, support at all levels is critical and the caregivers' description of this adds a clearer picture of how it contributes to a stronger sense of support for them. Both will be explored further in this chapter.

The chapter will also discuss implications of the findings for practice, policy and research related to support networks. As well, limitations of the research will be presented, directions for future research and finally, the conclusions will be outlined.

Integration and Insights

The five major roles that arose in this research were discussed in the literature related to the care of people living with dementia however, the literature describes the major roles more as it relates to the effects they have on the person living with dementia and only to some degree on how the major roles impact the well-being of their caregiver. The 2019 report "Improving the

Quality of Life of People Living with Dementia and their Caregivers" (Canadian Academy of Health Sciences) is a review of the latest research, programs and policies addressing the needs of people living with dementia and their caregivers. This report outlines a coordinated approach to addressing medical, social and policy areas of the care of people living with dementia. The report's findings are similar to and support this research's major roles, however they are not specific to understanding the role of support networks. The importance of people living with dementia and their caregivers remaining involved with community activities as contributing to their quality of life is discussed in this report. The major roles are not connected to the support networks of the informal caregivers of people living with dementia in this report or in the literature generally. As well the role of the community in influencing support networks for informal caregivers of people living with dementia has not been explored extensively in the literature. This discussion section will look at each role in relation to these two areas, the role of the support network of informal caregivers of people living with dementia and the role of the community in these support networks. This brings new understanding to support networks for informal caregivers of a loved one living with dementia.

Addressing the Stigma of Dementia.

The first major role is about the advocacy that caregivers identified as being needed to combat the stigma of a dementia diagnosis. A stigma of dementia is recognized in the literature as contributing to social isolation of both the caregiver and those living with dementia (Egdell, 2012; Zeilig, 2015). The literature also describes the delay in diagnosis of dementia and the lack of support from healthcare providers which stems from the stigma (Egdell, 2012; Gallagher-Thompson et al., 2012). There was a lack of literature that connected participating in advocacy to the role of support networks. Caregivers said to ensure appropriate diagnosis, good quality care and inclusion in daily activities there needs to be advocacy on behalf of the person with dementia. They identified that this advocacy required a significant amount of their time and emotional energy. Caregivers described the reduction of the stigma of dementia as contributing to three areas of support. It would ease their daily interactions by reducing how much explanation was needed regarding dementia, assistance from others would be more readily identified and offered, and there would be a greater acceptance of the person living with dementia by their community.

Participation in advocacy to address stigma was identified by caregivers as a role for family, friends, communities, healthcare and support system members of their support networks. This participation would help to increase the awareness of those in the support network of the impact of stigma on the daily lives of informal caregivers and the person with dementia, and the amount of time and energy the caregiver spends on advocacy for this reason.

The support network's involvement in advocacy would relieve some of the time burden on the caregiver while also demonstrating an understanding of the impact of the stigma. The literature does speak about public education campaigns to raise awareness of dementia (WHO, 2014), however the research on increasing the capacity of communities to respond to the needs of informal caregivers is a new and emerging area. Crampton and Eley (2013) describe their initial findings from a scoping project that explored how one city could become a dementia-friendly community. It outlines that what is good for a person living with dementia is good for everyone, increased awareness and changing negative stereotypes is needed, and that training about dementia is needed in all sectors. Their study (Crampton & Eley, 2013) is one of only a few projects that are looking at the communities' role in dementia care and it did not look at the impact of the support network of the informal caregiver. The second major role of understanding dementia and sharing this understanding was seen by caregivers as one way of addressing stigma and informing the role of being an advocate.

Understanding Dementia.

Understanding dementia and sharing this knowledge is a critical component of caregivers feeling supported by all support network members. Understanding dementia includes learning about the disease, its' progression, and what good quality care and interaction with the person with dementia looks like. As well, it is about understanding the importance of social interaction and physical activity in optimizing the health of the person with dementia. Within the literature, the need to increase the understanding of dementia focuses on the need to increase the skills of caregivers (Gallagher-Thompson et al., 2012; Zhang et al., 2014) and health care providers (Gallagher-Thompson et al., 2012; Lopez-Hartmann et al., 2012). Again, the literature is growing in the promotion of dementia friendly communities (Crampton & Eley, 2013) but there remains a lack of literature looking at the role of support networks to facilitate understanding dementia better. In this research, the caregivers spoke about the increasing amount of time that they spend educating the members of their support networks about dementia, its' progression and the changing needs of both the caregiver and person living with dementia over the course of the disease. They described the relief and support they felt when support network members educated themselves and others about dementia. This relieved the caregivers of educating support network members, it established trust that the network member would treat the person with dementia with respect and interest, and allowed interaction with the caregiver to focus on what the caregiver needed and wanted to explore. Caregivers expressed that when community groups understood dementia it allowed the caregiver and person with dementia to stay involved in activities. This reduced their social isolation, supported the caregiver in retaining activities important to them and helped to relieve caregiver stress.

Caregivers spoke of the limited resources that are available to formal support groups, such as fundraising expertise and government funding, to increase the understanding of dementia. As well caregivers identified the need for health and social services to increase their understanding of dementia. They felt that an increased investment in this education would increase the support they received from friends, communities and services. As social isolation is increasingly being recognized as a risk factor in declining health for caregivers and people with dementia (Egdell, 2012), an increase in the support networks capacity may assist the person with dementia to stay in the community longer rather than having to move to a facility setting. The role of support networks of informal caregivers in understanding dementia and sharing that knowledge was described by caregivers as a critical element in their sense of support and in recognizing the value of the caregiver's time. In the first two major roles caregivers said that large amounts of time were spent in advocacy and increasing understanding of dementia to family and friends. They described the time it took to manage the lack of understanding within community settings as stressful and often it did not result in increased understanding. This time burden is in addition to the time caregivers are providing direct care to the person living with dementia. The third major role of accessing and coordinating information is also described by caregivers as being very time intensive.

Accessing and Coordinating Resources.

The third major role of assisting to access and coordinate resources was described by caregivers as an ongoing process of anticipating what resources they and the person with dementia will need as the disease progresses and often they said that they were not keeping up with the changes. Literature in this area is limited to acknowledging this need (Gallagher-Thompson et al., 2012; Lopez-Hartmann et al., 2012), and to connecting to formal support groups (Alzheimer's Society of Alberta and Northwest Territories, 2017). The role of support networks and specifically the role of community in assisting with accessing and coordinating information and resources was not found in the literature. The loss of the core member of the caregiver's support network and the impact of this loss on accessing and coordinating resources was also discussed in this role. The role the person with dementia had played in their household in carrying out chores, sharing new information or being able to address new challenges gradually disappears. This leaves the caregiver with the responsibility to carry out these roles. Caregivers discussed the desire for their support network members to assume some of these responsibilities as well as help the caregiver to learn how to manage other activities. Caregivers also said that when their support network understood dementia, then the members could help caregivers anticipate changes and provide support in decision making more easily about resources.

Caregivers described an interrelationship existing between the first three roles. For example, caregivers identified three areas of interrelationships across these roles. They are: the recognition of the consumption of the caregiver's time; the caregiver and support network responding to the progression of the disease at the same time; and the community's absence as a significant factor in reducing the sense of support for caregivers. The following fourth role of providing care is also closely linked to the first three roles through the recognition that as the disease progresses the amount of care increases also, and that with an increased understanding of dementia, support network members feel better able to provide good quality care.

Providing Care to the Person Living with Dementia.

The trusting relationships between caregivers and their support networks are the basis for caregivers feeling confident that their support network will provide good interactions and good quality care for the person with dementia. The literature related to this fourth major role focuses on the role of specific members of a support network. For example, health care provider's skills in social interaction and hands on care activities are discussed often in the literature (Salin & Astedt-Kurki, 2009). As well the role of family providing care is well reviewed (Meyer & Bergen, 2016). But there is a gap in the literature about friends and communities' role in providing care. The role of the community in accommodating the needs of the person living with dementia in activities is a new emerging area and was identified by caregivers as an opportunity to increase care provision alternatives especially for people living with dementia in the early stages of the disease. When all members of a support network are able to provide care to some degree then the caregivers described feeling more fully supported. The final role continues the recognition that all support network members are essential to providing a sense of support to caregivers by tying together all five roles in the coordination of support at all levels.

Coordination of Support at All Levels.

The fifth and final major role responding to the question about the role of support networks in the lives of informal caregivers of people living with dementia was expressed by the caregivers as needing support from family, friends, communities, service providers, from societal values and from relevant policies. The caregivers said that this support was needed across all the roles for them to feel fully supported in their role as an informal caregiver to a person with dementia. They used the phrase support coming from "all levels" to describe this need. The literature speaks to support in specific areas such as education for caregivers and ensuring the informal caregiver is part of the health team (Gallagher-Thompson et al., 2012), the caregiver's willingness to accept help (Boots et al., 2015), the impact of being a caregiver on their work life (Schroeder et al., 2012) and the impact of homecare (Gethin-Jones, 2014). There was not literature however, on the role of support network members assisting with coordination among the network's members. For example, in this study caregivers spoke about coordination involving good communication between support network members, them working as a team, coordinating the provision of care and following up on who was assisting with individual practical activities. This coordination also involved caregivers hearing about programs at the community and societal levels to address the stigma of dementia and about public education campaigns to increase the understanding of dementia. Caregivers, in this study, recognized the feedback loop that occurs when the stigma of dementia is decreased, along with an increase in the understanding of dementia on a societal level, this then results in an increase in the capacity of their network to provide support. Policies that address public education and increased understanding of dementia across family, friends, the community and the healthcare system are a key part of the coordination at all levels by providing a foundation and structure that can adapt as knowledge increases and needs change.

This structure assists the support network to build strong ties across the multiple relationships within a support network. These relationships occur between network members and the caregiver, among the network members themselves, and with the person living with dementia. Maintaining these relationships, understanding how to effectively support both the caregiver and the person with dementia and at the same time ensuring that network members recognize their own personal limits adds complexity to creating and sustaining an effective support network.

In this role, caregivers also described the gap that exists if one member of the network is not able to provide support. For example, one of the caregivers spoke about cancelling her own medical appointments when formal services and family were not available at the time she needed. Caregivers said that because of this gap they felt a decrease in support and they looked to other network members to increase support. Caregivers described needing support that encircles the caregiver and recognizes the caregiver's needs. This more integrated approach for the role of the support network has the potential to create a flexible network where the members have the knowledge and connections to provide support to caregivers as the disease continually progresses.

Summary of Major Roles.

The discussion of the five major roles facilitated insights and conclusions to be drawn about the research question: what is the role of support networks in the lives of informal caregivers of people living with dementia? The context for the roles was described through the two sub questions: how do caregivers see support and what factors influence the role of the support networks? These sub questions acted as the context of the research question and they contributed to further understanding the five roles that emerged out of this research.

The five major roles that emerged from the data identify the roles caregivers described their support networks played in their lives being: participating in advocacy against the stigma of dementia, understanding dementia, assisting caregivers to access and coordinate resources, providing care, and coordinating support at all levels. Two areas which emerged as playing a significant role in the caregiver's sense of support are first the recognition that the support of the community is a key element in the informal caregivers' sense of support but the community has often withdrawn and is absent as part of the support network. The second new insight is that support at all levels is critical because when all levels are involved in providing support, the support network can adapt to changes in support needs as the disease progresses. This results in the caregiver feeling supported. The caregivers' description of this insight adds a clearer picture of how it contributes to their sense of support. The discussion of these emerging roles begins to demonstrate the implications for practice in developing and sustaining support networks, policies that affect support networks and future research on support networks.

Implications

This research examined the role of support networks of informal caregivers of people living with dementia. The perspective of the participants in this research helps to shed light on practice implications for the development and sustainability of support networks, and new directions for policy development.

Practice Implications.

Practice implications of this research for health and social programs include developing skills to sustain support networks through increased community involvement such as developing recreational programs targeting informal caregivers and educating businesses about dementia. As well, a second area of practice is the development of engagement strategies to assist support network members to recognize their roles and become active in them. For example, formal support groups, such as those provided by the Alzheimer's Society of Alberta and Northwest Territories, holding education sessions for support network members to increase their knowledge of health and social services. As well, education for health and social service providers on how to be effective members of a support network.

Policy Implications.

There are two main policy areas that are impacted by this research. The first is addressing the social impacts of being an informal caregiver. For example, one of the caregivers described this time of her life as being at a new “developmental phase of a family”. She compared it to families with young children and the societal supports that are built for that developmental phase including playgrounds, immunization programs, or transportation options. Policies that look at social interaction, transportation needs, physical activity and care needs of informal caregivers and the person with dementia could help to build a supportive structure for this developmental phase of families.

A second policy area emerging out of this research addresses the ability to share personal information across the members of the support network. Policies that support good communication of required information, such as what are the care options available in the community, between informal caregivers, family, friends, communities and health and social services would assist in developing resilient support networks. A resilient support network can adapt to the progression of the disease of dementia and adjust to changes of membership within the network itself.

Study Limitations.

This research has several limiting factors. The sample size is small at six participants and the caregivers also all represent Caucasian middle class people living within the same urban setting. Research that compares the experiences of caregivers within rural settings, with diverse cultural backgrounds and differing income levels could add to an increased understanding of the similarities and differences in support networks across these groups.

This research documents caregiver's perceptions in one time-period only. Although there were two interviews conducted with each caregiver at two different times, in general they were only weeks apart. A longitudinal study would increase the knowledge of how the progression of dementia impacts the aspects of social networks for caregivers discussed in this research. Also, it may show how support networks can adapt to changes in the caregiver and their support network.

The last limitation of this study is that three of the six informal caregivers belong to the same church. There would be the opportunity for these caregivers to meet at church and this may influence how they perceive their support networks.

Future Research.

As a result of this study's findings and the limitations, there are several areas in which future research could take place. Further exploration of how community members can be involved in support networks is needed. The communities' role in providing support may also impact informal caregivers of other vulnerable populations such as older adults with multiple chronic conditions.

Understanding how support network members can most effectively provide coordination of their roles would also help build strong support networks. Finally, exploring the impact of the loss of the core member of the caregiver's support network to a diagnosis of dementia could increase the understanding of how both the informal caregiver and their support network are adapting to this change.

Concluding Remarks

The question that is explored in this research is what is the role of support networks in the lives of informal caregivers of people living with dementia? The two sub questions of how do caregivers see support and what factors influence the role of support networks provided the context for this question. Caregivers identified five roles for their support network members in this research. The roles are to participate in advocacy to combat stigma of the dementia diagnosis, to understand and help others understand dementia, to assist in accessing and coordinating resources, to provide care to the person with dementia, and to help to coordinate support at all levels. Two areas emerged as contributing new knowledge to this area: the recognition that the support of the community is a key element in informal caregivers' sense of support but the community has often withdrawn and is absent as part of the support network; and support at all levels is critical and the informal caregivers' description of this area adds a clearer picture of how this broader support contributes to their overall sense of support.

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Appendix A: Recruitment Materials

University of Alberta

The Role of Support Networks in the lives of Caregivers of People living with Dementia.

Information Sheet

Research Investigator:
Helen Lightfoot
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Supervisor (if applicable:
Kyle Y. Whitfield PhD., RPP-MCIP (Registered Professional Planner)
Associate Professor
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Ph. 780-492-0165

Thank you for taking the time to read about this exciting research. I am a Masters of Arts in Community Engagement student in the Faculty of Extension and I have been working in home care for 25 years. I am committed to learning about the best ways to support the important and rewarding work of informal caregivers.

As part of my thesis I am researching the role that support networks play in the lives of caregivers of people living with dementia. There is a recognition that support networks help caregivers to maintain their physical and mental health. At the same time, there is a strong trend towards social isolation as the disease of dementia progresses. I will be interviewing caregivers about who is part of their support networks, what roles are played by the support network and what aspects of those roles provide a sense of being supported.

I am hoping you will consider participating in this research with me. You would be committing to 2 - one hour interviews with myself at a location convenient to you i.e. coffee shop, meeting room at an agency. The interview will be audiotaped. The information from the interviews will form the basis of the final thesis without the use of personally identifying information. The individual interviews will be kept confidential.

I am very excited to be able to hear from caregivers about their support networks and to learn more about this important area. If you think you may be willing to participate in this research study, please contact myself, Helen Lightfoot, at hlightfo@ualberta.ca and I will call you to provide more information.

A couple of service providers have generously promoted participation in this research for me and while I am very passionate about this study it may not be of interest to you at this time. Please know that if you do not want to participate it will not affect your involvement with these service providers.

I appreciate you considering becoming involved. Thank you.

Helen Lightfoot

Appendix B: Invitation to Participate

University of Alberta

INFORMATION SHEET

Study Title: The role of support networks in the lives of informal caregivers of people living with dementia

Research Investigator:
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Background
Care partner support is an important topic in the management of chronic disease, thank you for your interest in my research project. I have been working in home-care for 25 years and have seen first-hand the difficulties that families face. As part of my master's thesis I am now looking at the role that support networks play in the lives of care partners of people living with dementia.

There is a growing recognition that support networks help care partners maintain their physical and psychological health. At the same time, there is a strong trend towards social isolation as the dementia process progresses. I plan to interview 5- 10 caregivers about their support networks and how those networks contribute to their physical and psychological wellbeing.

I am hoping that you will consider participating in this research with me. You would be committing to 2 one-hour interviews with me in a location convenient to you (e.g., coffee shop, meeting room at an agency). The interview will be audiotaped. The information from the interviews will be analyzed and later submitted for publication. Your participation will be confidential and no personal identifying information will be released.

You may also receive information about this study from the Alzheimer's Society of Alberta and Northwest Territories (ASANT) who have generously agreed to promote this study. While I am passionate about this topic I can appreciate that this may not be of interest to you right now. Whether you choose to participate or not will be kept confidential; it will not affect your relationship with ASANT.

Purpose

This study will contribute to understanding how to effectively support informal care partners on an individual, community and policy basis.

Study Procedures

The first interview will include the following four questions and general discussion.

As a care partner:

- Who is a part of your support network?
- What roles do they play in your life?
- What does support mean to you?
- How do your support networks contribute to your feelings of support?

The second interview will further explore the ideas and stories that were part of the first interview.

All interviews will be audio-taped and I will transcribe them. Myself and my supervisor will review the transcripts to identify commonalities and differences among all of interviews. These themes will form the basis of my Master Thesis.

Benefits

There is no direct benefit that you will receive from participating in this study. We hope that the information we get from this study will help us better understand how to support informal caregivers.

Risk

Sharing your stories of caregiving and your support networks may bring up a wide range of emotions. Resources for support will be available.

Voluntary Participation

Participation in this study is completely voluntary and you can decide what information you do or do not want to provide. You can withdraw from the study at any time. You can ask to have your information removed from the study up until 2 weeks after the interview has been transcribed. The audio recording will be erased and the transcripts will be shredded.

Confidentiality & Anonymity

This research will be used as the basis of my Master's Thesis. It will also be part of a published article and presentations.

The data will be kept confidential with only myself and my supervisor having access to it.

Individual participants will not be identified in the data. The transcribed data will be kept in a secure place and the audio recordings will be stored with password protection for at least 5 years following the end of

the research project. When appropriate the transcriptions will be shredded and the audio recording will be erased.
A summary of the research will be available to participants. Participants will be asked if they would like the summary at the time of the interview. They will also be able to email myself and request the summary after the interviews.

Further Information
If you have any further questions regarding this study, please do not hesitate to contact Helen Lightfoot at hlightfo@ualberta.ca.

The plan for this study has been reviewed by a Research Ethics Board at the University of Alberta. If you have questions about your rights or how research should be conducted, you can call (780) 492-2615. This office is independent of the researchers.

Consent Statement
I have read this form and the research study has been explained to me. I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact. I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

____	_______________
Participant's Name (printed) and Signature	Date
____	_______________
Name (printed) and Signature of Person Obtaining Consent	Date

Appendix C: Free and Informed Consent

Consent Form

Title of Research Project: The Role Support Networks Play in the Lives of Informal Caregivers of People Living with Dementia

Research Investigator:
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Please circle your answers:

Have you read and received the Information Sheet?	Yes	No
Do you understand the benefits and risks involved in taking part in this study?	Yes	No
Have you had an opportunity to ask questions and discuss this study?	Yes	No
Do you understand that you can quit taking part at any point during the interview?	Yes	No
Do you understand that you can withdraw at any time during the data collection part of the study and that any comments that you provided up to that point will not be used?	Yes	No
Has confidentiality been explained to you?	Yes	No
Do you understand who will have access to the data collected?	Yes	No
Do you know that the information that you provide will be used for a class presentation and then destroyed?	Yes	No
Do you understand that the interviews will be audio recorded and transcribed?	Yes	No
Do you understand that you have up until the end of the day of your interview to withdraw what you have shared in the interview?	Yes	No

If you have further questions regarding the research, please contact the student listed above.

This study was explained to me by: ________________________________

I agree to take part in this study.

______________________________ _____________________
Signature of Research Participant Date (dd/mm/yyyy)

____
Printed name

The plan for this study has been reviewed for its adherence to ethical guidelines by a Research Ethics Board at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Research Ethics Office at (780) 492-2615.

Appendix D: Letter of Support – 1

Alberta Health Services

RE: Support for 2017 SPOR Graduate Studentship Application of Helen Lightfoot

Dear Dr. Whitfield,

On behalf of the AHS Seniors Health Strategic Clinical NetworkTM (SCN), we are pleased to provide our support for the SPOR Graduate Studentship application submitted for Helen Lightfoot, addressing the informal support networks of caregivers.

We believe that this proposal, if successful, will contribute to the achievement of our SCN's mission: to make improvements to health care services and practices that enable Alberta seniors to optimize their health, well-being and independence. Patient-oriented research is vital to ensuring that new evidence generated through research is focused on the needs of patients and is integrated into the healthcare system and clinical practice.

Helen's proposal is aligned with our "Aging Brain Care" platform. There is a growing recognition of the need to better support the caregivers of people with dementia. A better understanding of the support networks of caregivers, and how those networks adapt or change over time, may inform the development of future interventions to support caregivers.

We are pleased to join you in this undertaking as a community partner. We can offer guidance on recruitment of caregivers to your qualitative interviews. We would also be an interested knowledge user for the findings of this research, as it may support our own efforts to support caregivers of older adults. We wish you success with this application.

Sincerely,

Dr. Jim Silvius Senior Medical Director Seniors Health SCNTM
Alberta Health Services

Dr. Adrian Wagg Scientific Director Seniors Health SCNTM Alberta
Health Services

Dr. James Silvius, Senior Medical Director Seniors Health Strategic
Clinical NetworkTM 10101 Southport Lane SW Calgary, AB T2W 3N2
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September 20, 2017

Dr. Kyle Whitfield Faculty of Extension 2-215 Enterprise Square
Edmonton, AB T5J 4P6

Appendix E: Letter of Support - 2

Hi Helen,

We can definitely assist you with this. We are currently recruiting for two other projects, one will be finished in February, so I don't see that being a problem.

Let me know more details as to when you want to start recruiting, how many care partners, etc...

Thanks,

Arlene Huhn
Manager, Client Services & Programs
10531 Kingsway Ave
Edmonton, AB T5M 1T6
780-488-2266, ext.224
1-866-950-5465

Hello Arlene,

This email is in follow up to our brief conversation this past week.
I am embarking on a qualitative research project for my Masters of Arts in Community Engagement (MACE).
I will be exploring the role of support networks in the lives of care partners of people living with dementia.
A review of literature shows that support networks play a role in maintaining the physical, emotional and mental health of care partners.
At the same time there is a very strong trend of increasing social isolation of care partners of people living with dementia as the disease progresses.
I will be interviewing care partners to explore who is part of their networks and what role the network plays in their lives in an effort to learn about what factors care partners believe help to maintain support networks and reduce social isolation.

The Alzheimer's Society of Alberta and Northwest Territories (ASANT) plays a key role in supporting people living with dementia and their care partners through education, socialization and community development.
Would ASANT be interested in supporting my project through recruitment of participants and reviewing the outcomes of the research?

Thank you for your interest.

Helen Lightfoot
MACE student