

The three faces of loss: The cost of caring for a family member with Dementia

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The long term outcome of Alzheimer's and related dementia (ADRD) is the eventual and complete dependence upon care givers, most often family or friends. There are costs to providing the kind of care needed to support and keep someone with ADRD at home safely. We conducted one-on-one interviews with 19 health care providers and 19 family/friend caregivers. Using thematic analysis to interpret the data we discovered that the cost

of caring had three dimensions: physical, emotional, and financial. These dimensions often overlap as the cost of caring is often multi-faceted and complicated. Women are particularly affected by the role of caregiving as it frequently falls to them, they tend to juggle more responsibilities at once, and are affected by relationship history and a sense of obligation. We discuss these dimensions, providing recommendations for both health care providers and family/friend caregivers.

Key Words: *Alzheimer's disease; Caregiver burden; Family/friend caregivers; Health care providers*

INTRODUCTION

Alzheimer's disease and related dementia (ADRD) are increasing in incidence globally; by 2031 there will be 937,000 people living with dementia in Canada (1). The burden associated with living with dementia is multi-faceted involving the lives of multiple people (2). Family caregivers are described as "providing unpaid help or care to any person who need not live with you" (3). Family/friend caregivers of people living with memory loss report feelings of guilt, fatigue, frustration, fear, isolation, and hopelessness (4-7). High levels of stress for caregivers are associated with many chronic illness caregiving experiences, more so when the care recipient is living with ADRD (5). The long-term and inevitable consequence of ADRD is complete dependence of the patient on a caregiver. The caregiver in most cases is a female family member, often the spouse, a child, or close relative. Family/friend caregivers tend to be ill-equipped with the specialized skills or training that would help them with the relentless and exhausting process of caring for someone with progressive dementia (8). The significant demands of the job of caregiving and desire by family members to 'do the right thing' frequently results in family/friend caregivers being coined "the invisible second patient" (9). Family/friend caregivers experience distress and poorer quality of life as a result of taking care of someone with ADRD. There is an undeniable burden of the multifaceted cost to caring for people living with dementia and their families. Health care providers should consider the array of emotions experienced by family/friend caregivers and engage in family-centred care, acknowledging and working to alleviate unnecessary caregiving burden. A team of nurse researchers conducted a qualitative research study in which both health care providers and family/friend caregivers of people with ADRD in New Brunswick, Canada were interviewed, asking about the experiences of providing care to a family member or friend. We found that family/friend caregivers identified that there were a number of factors that contributed to the cost of providing care to someone living with dementia. The cost of caring had three dimensions: physical, emotional, and financial. In this article, we describe the study briefly and provide a discussion about these dimensions, concluding by offering some suggestions for health care providers who interact with family/friend caregivers.

Much research has focused on the physiological, cognitive, and emotional trajectory of ADRD, and how it influences caregiving for these individuals (4,6,10). Less is known about the cost to the family/friend caregiver who provides care to the person living with ADRD. Recent literature indicates that ADRD is associated with a level of stigma that was unexpected (11). The shame and secrecy that surrounds the diagnosis is felt by and impedes caregiver's willingness to reach out for help.

Caring has been and continues to be a 'deeply feminized issue' with women

facing greater expectations to care for family than men (12). Globally women spend two to ten times more time than men in caring for others (13). Family/friend caregiving is most prevalent among middle-aged women, often the daughter or spouse of the person with ADRD (14,15). Munkeford et al. (16) found that women feel societal pressure to take on additional responsibilities associated with caring for family members with dementia without regard for their own well-being. Women feel completely abandoned by health care providers who failed to acknowledge the stress and negative factors of caring for a loved one (16). It is not surprising to learn that female caregivers experience higher rates of depression, unmet personal needs, and physical illnesses, especially stress related illnesses (10,17).

There is a growing realization that home-based care is both desired and better for the people involved, and more cost effective than institutional care (16), which is just one more reason why keeping people with ADRD at home with the appropriate supports makes the utmost sense. The focus of care should be on community-based care in which people are able to age-in-place regardless of a diagnosis that will incrementally require more resources and supports (18,19).

RESEARCH METHODOLOGY

We used a qualitative approach as little research has occurred in New Brunswick about the physical, emotional, and financial costs of providing care to someone with Alzheimer's disease and related dementias (ADRDs). Literature supports the use of a qualitative design in many situations including: to guarantee the opinions of marginalized people are heard (20,21), to increase awareness of the experiences of people with dementia (22), to understand active aging (23), and to answer questions about experiences, meanings, and perspectives (24).

Data Collection

After receiving ethics review, data collection occurred in two phases. All data was collected between 2016 and 2017. In phase one, participants (family/friend caregivers and health care providers(HCP)) were recruited through advertisements in public locations. In phase two, a community organization providing services to people with ADRD notified potential participants about the study and provided contact details so interested participants could contact the research team for additional information. Most participants were recruited during phase one of the recruitment process.

Two semi-structured interview guides were developed. One was for the family/friend caregivers and the other for health care providers. Both guides were developed collaboratively with community stakeholders.

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Participants

Participants in the family/friend caregiver group had to be responsible for the emotional and/or instrumental care for a person with ADRD without receiving payment. Health care providers needed to have a formal health credential such as an RN, MD, or LPN. All participants needed to be able to speak English and be over the age of eighteen. Details of both groups of participants are provided in the following Tables 1 and 2.

Analysis

Braun and Clarke's (25) approach to thematic analysis was utilized. Each

TABLE 1

Descriptive Statistics for Family/Friend Caregivers for Qualitative Interviews (N=19)

Characteristics	Phase 1 General Recruitment (n=12)	Phase 2 Community Organization Recruitment (n=7)
Sex		
Male	2 (16.7%)	1 (14.3%)
Female	10 (83.3%)	6 (85.7%)
Age in years		
Median (Range)	63.0 (45 to 78 years)	70.0 (49 to 78 years)
Place of residence		
Rural area	3 (25.0%)	2 (28.6%)
Small town	2 (16.7%)	2 (28.6%)
City	7 (58.3%)	3 (42.9%)
Relationship to person with dementia		
Child	6 (50.0%)	2 (28.6%)
Spouse	5 (41.7%)	4 (57.1%)
Other family member	0 (0.0%)	1 (14.3%)
Friend	1 (8.3%)	0 (0.0%)
Live with person with dementia		
No	4 (33.3%)	4 (57.1%)
Yes	8 (66.7%)	3 (42.9%)
Person with Dementia		
Sex		
Male	6 (50.0%)	4 (57.1%)
Female	6 (50.0%)	3 (42.9%)
Age in years		
Median (Range)	85.0 (72 to 89 years)	77.0 (66 to 88 years)
Years since memory loss noticed		
Median (Range)	6.5 (3 to 10 years)	5.0 (2 to 13 years)
Diagnosed by MD or NP		
No	3 (25.0%)	0 (0.0%)
Yes	9 (75.0%)	7 (100.0%)
Years since diagnosis		
Median (Range)	3.0 (0 to 8 years)	3.0 (1 to 11 years)
Number included in analysis	n=9	n=7
Global Deterioration Scale¹		
Median (Range)	4.0 (2.0 to 6.5)	4.5 (4.0 to 7.0)

(¹Scale 1 to 7 with 1 being 'no cognitive deterioration' and 7 being 'very severe deterioration')

TABLE 2

Descriptive Statistics for Health care Providers for Qualitative Interviews (N=19).

Characteristics	Phase 1 General Recruitment (n=10)	Phase 2 Recruit Alzheimer Society (n=9)
Sex		
Male	2 (20.0%)	2 (22.2%)
Female	8 (80.0%)	7 (77.8%)
Age in years		
Median (Range)	53.0 (49 to 67 years) (n=9)	36.0 (26 to 57 years)
Professional group		
Medical Physician	1 (10.0%)	3 (33.3%)
Nurse Practitioner	2 (20.0%)	0 (0.0%)
Registered Nurse	6 (60.0%)	3 (33.3%)
Licensed Practical Nurse	1 (10.0%)	2 (22.2%)
Registered Social Worker	0 (0.0%)	1 (11.1%)
Specialty area		
Family Medicine	1 (10.0%)	2 (22.2%)
Geriatrics	4 (40.0%)	3 (33.3%)
Psychiatrics / Mental Health	1 (10.0%)	1 (11.1%)
Long Term Care	1 (10.0%)	1 (11.1%)
Community / Extra-Mural	0 (0.0%)	1 (11.1%)
Memory Care	0 (0.0%)	1 (11.1%)
Not Applicable	3 (30.0%)	0 (0.0%)
Years in practice		
Less than 1 year	0 (0.0%)	2 (22.2%)
1 to 5 years	0 (0.0%)	2 (22.2%)
5 to 10 years	1 (10.0%)	0 (0.0%)
10 to 20 years	0 (0.0%)	2 (22.2%)
More than 20 years	9 (90.0%)	3 (33.3%)
Approx. % patients with memory loss		
Median (Range)	80.0% (5% to 100%)	50.0% (5% to 90%)
Location of practice		
Rural area	2 (20.0%)	1 (11.1%)
Small town	1 (10.0%)	1 (11.1%)
City	7 (70.0%)	7 (77.8%)

interview was transcribed verbatim and checked for accuracy. Following this, two to three members of the research team coded interviews on a line-by-line basis. Team members met to share coding decisions and agreed on initial codes. When discrepancies in coding occurred, a consensus was reached. The codes were then examined for patterns and collapsed and re-collapsed as necessary to develop themes. We used QRS NVivo 10 software to organize the data and maintain an audit trail. Additionally, rigor was maintained by reflecting on the eight criteria outlined by Tracey (26). For example, credibility was established through thick description, and the development of a digital coding book that defined codes and themes. Reflexivity was maintained through regular team discussions and keeping a record of all methodological and theoretical decisions.

RESULTS AND FINDINGS

We describe the three dimensions of the cost of caring: emotional, physical, and financial, providing exemplars from the data to help illustrate the significance to the caregivers. In many situations the cost of caring included

overlap between more than one of the three dimensions. As an example, when participants could not find time to take care of themselves, they described both the physical and emotional repercussions of the situation. We did not include any names or identifiers in order to protect the identity of the participants.

Emotional cost of caring

Memory loss resulted in the 'virtual' loss of a loved one's spirit and personality. As the decline in memory and function increased for the person with ADRD, the family/friend caregiver responsibility of providing physical care for the challenges of a progressively frail body also increased. The most common types of emotional costs of caring included sadness, loss, grief, frustration, loneliness and abandonment. As one person said, "oh it's just the frustration of having someone that used to be a friend that helped and could talk, that is no longer there. Just sitting in front of you deteriorating, that is terribly, terribly, ...it's sad." It typifies some of the feelings of emotional burden expressed by family caregivers.

The predominant message received from the family/friend caregivers was the feeling of "doing all of this alone." The benefits of having help was certainly fundamental to being able to continue in the caregiver role; "Just knowing that there's someone else. That I'm not the lone wolf out there." Many caregiver children felt trapped and responsible for the care of their loved-one, while others saw it as a responsibility transition for adult children in caring for aging parents; "you start to realize the roles are reversed now, I'm the parent and she is the child and that's how I took it; now it's my time to take care of you", which speaks to the sense of obligation that family/friend caregivers often feel. Another spouse made reference to their wedding vows "I realize I'm in this for better or worse." The spouses of people with memory loss assumed the responsibility of caring as part of the vows they took in marriage and a reciprocal desire to look after each other. "Well, he's taken care of me for 50 years. I think it's my turn to take care of him."

Family members were frustrated by the lack of direction provided to them by the health care/social service system about caring for someone with memory loss. A common message was, "if we knew what it would take to care for NAME, we would have gotten help much sooner." Families needed time to digest the diagnosis, which meant a number of additional follow-up visits with health care providers vital to the ability to understand the trajectory of the disease, what to expect, and how to provide the best care. "It's not so much the people experiencing the memory loss, but for the family and the caregivers, of what should be expected." It is important for health care providers to understand the financial, physical, and emotional toll of being a family/friend caregivers. Being able to identify and offer resources to facilitate the physical component of the provision of continued care for someone with ADRD is an important role for the health care providers. An important benefit of a service for people living with ADRD is explained by an HCP:

And consequently it's overwhelming for those people to hear everything there is to know about dementia and understanding all of the nuances of that, so First Link [a service offering resources] is a way for them particularly because there's built in a kind of three week lag time, it gives people an opportunity to kind of process and digest and understand what they've been told and figure out what their questions may be...

Many family/friend caregivers referred to the frustration of not getting the health care they thought was important, and/or available. Early diagnosis is critical in becoming prepared to care, initiating vital medication therapy, understanding the disease better and putting services in place (27). We also know that the subtlety of symptoms, the ability of the person with ADRD to hide their symptoms and the overall stigma and discrimination are barriers to obtaining an early diagnosis (2,27). A daughter shared concern over the progression of their mother's disease and the lack of access to appropriate care:

When something can be slowed down, prevented or just having the awareness of this..., this is a condition that exists in a person that you love. So, then to cope with that right, and for a doctor, for the medical system to say, no we don't until a person is like, you know, not dressing themselves or don't care about their, you know...cleanliness...

Another person said they were told "and [HCP] said not to bring her back until she is in a much worse state", a statement contributing to frustration, sense of abandonment, and growing distrust of the health care system.

The role of caregiving frequently falls to women in the family, either the wife or the eldest, single, or geographically closest daughter (9). The fact that women become the caregivers more often than men speaks to the gendered

aspects of women's tendency to outlive men, socialization towards nurturing and caring, well entrenched and traditional roles within the family, and ideas that the careers of women are less important than those of men (28). Women stated that they felt completely overwhelmed by the amount of work and time involved when responsible for the running of two households. A daughter said, "that constant business that a working ... a mother who is working full-time is already doing all of these things for her own family and now I'm doing a lot of those for him as well." Women with young families identified themselves as the 'sandwich generation' when they suddenly become responsible for both their family and parents. A daughter said:

...that middle group of people, between the elderly and the young have got such packed lives in order to meet the current bills, education for children, and they are really torn with their own immediate families, their own mother[s] and father[s], who are usually elderly."

The lives of women were frequently put on hold as they struggled with the day-to-day work of caring, as a wife stated:

I'm kind of taking it day-by-day and whatever I'm handed tomorrow I will deal with tomorrow, you know, that's the ...that's the philosophy that I'm living with right now because I don't want the stress of thinking too far in advance.

Another woman stated that sometimes it is frustrating and hard to accept that things are not the way they used to be with her husband, "Well, I do all the cooking and have to take full responsibility of where we go, when we go, how we go, setting deadlines...all those types of things." The previous quotes highlight both the emotional and physical toll that taking care of two families can have on family/friend caregivers.

There is a difference in caregiver exhaustion/burnout between women who felt a sense of obligation versus women who took the role on willingly (29,30). Women who provide care begrudgingly verbalized greater rates of loss, frustration, depression and anxiety. Women focused on the things they were losing rather than the opportunity to care for their loved one as a time-limited event in which they would eventually emerge to continue their lives. Women who have had difficult relationships with parents, especially when abuse was a dynamic of the relationship, experience far greater incidents of burn-out, stress, and chronic physical and mental health problems (29,30).

You become exhausted and then you can't do anything, you go through that period of exhaustion and you don't have the energy to lift yourself up and do something and so you let it ride again and then you know one day I just broke down.

Despite taking on the caring role through a sense of responsibility, women report both feelings of growth and satisfaction and ultimately recognize the significant emotional and physical toll of caring. Feelings of guilt and obligation caused significant amounts of worry, both of feeling unable to continue or of breaking a promise that they were no longer able to keep. A husband stated: "I promised her I would preserve her dignity and do what I can and preserving her dignity was not something I was able to do...It wasn't a promise I could keep." Many participants said that they might not have made these promises if they had had a little bit more direction from health care providers about what to expect from caregiving within the trajectory of the disease. The reality of having to make the decision to place a loved one in long-term care is recalled by a wife:

Because he always said to me, 'Please don't put me in a nursing home. Don't ever put me in a nursing home', and I said 'I promise you I won't dear, and I really meant it but I didn't realize that I was going to be living this situation.

Family/friend caregivers also mentioned the emotional toll of watching the slow and unrelenting decline of their family member, "I'm scared of a time when he maybe won't remember me or he won't remember our children" A family/friend caregiver described challenges with maintaining the relationship with her mother, "I'm losing my mom and the more I try to intervene, the worse I make our relationship."

Caring for a loved one caused many rifts in family dynamics such as loss of relationships with siblings, sufficient discord in marital relationships to cause breakdown, and resentment from partners and spouses about the temporal, emotional, and financial resources being consumed and demanded in providing the needed care:

It pretty much cost me my marriage because of all the pressures from all sides. My husband was as deep in this as I am and we had our own way of dealing with things, which did not strengthen the marriage...The marriage as it was is over, there's been too much damage.

Women do what is in front of them, but eventually realize the significant emotional and physical toll associated with caring for their loved ones, “Not only did I have the loss of my husband [to ADRD], but I had the loss of my place in society, my place in the work world...I lost both of those things at the same time.”

A HCP acknowledged the amount of stress and eventual burn-out that can come from trying to be the solo caregiver for someone with memory loss, “It can be very overwhelming to a family when they are diagnosed with a disease...and the onus is back on the family.” “There is a lot of family burnout in the community, a lot, yeah!” they continued, “because a full day with a person with memory loss is not a good thing. They need to have somewhere where they can vent to, as well.” Peer support was mentioned by both HCPs and family/friend caregivers as an intriguing and valuable opportunity to connect with other people facing similar situations.

The emotional costs of caring were exacerbated by previous relationship challenges, a lack of support by health care providers, and the concurrent physical costs of caring. Many women did not recognize that they were reaching the breaking point until it was too late.

Physical cost of caring

The physical costs of caring were frequently ignored by family members trying desperately to stay on top of the many tasks involved with caring for their loved one. For many, it included several changes to their regular routines to accommodate the many visits to health care providers and in order to fit in self-care, “it got to the point where I would get up at five in the morning and go to the gym while she’s still in bed.” The culmination of the progression of ADRD in their loved-one, the drastic change in routines and differing family dynamics contributed to the physical exhaustion they experienced, the toll it was taking on their own health, and the inability to find time to look after themselves, “I was diagnosed with fatigue...after all the changes in family dynamics, everything, the emotional and the physical strain.” A caregiver who suffers from a chronic condition herself explained how she experienced an exacerbation in her condition, “I have fibromyalgia and arthritis, which is very very bad and this is putting extra stress on it and it can cause my flare-ups”, while another caregiver stated that her “blood pressure began to spike” while experiencing the physical and mental exhaustion of caring for her mother

Numerous visits to HCPs during the investigation of memory loss and eventual diagnosis contributed to physical exhaustion for the caregivers, “it can be very demanding [for caregivers]...to go to their loved ones appointments and to keep up with their own work, their own appointments and their own lives.” Several HCP’s noted that caregivers sometimes put all the onus on themselves to care for their loved one, often pushing themselves to a breaking point all the while neglecting their own needs:

Caregivers...they suffer so much because they want to do it all and they don’t have the insight...it’s not sustainable, and then they burnout and everyone is unhappy. It’s sad because it doesn’t really have to go that way, but people have a hard time seeing the future when they are stuck in the middle.

Another health care professional stated:

Caregivers tend to put all of their energy into the person with dementia and neglect their own needs. Neglect their own social life. Neglect their own personal health. They’re at a higher risk for dementia themselves, so they’re at a higher risk for mental health issues and socialization.

Family/friend caregivers experienced significant fatigue, unmet personal needs, and little time to take care of themselves. Some only realized the impact after being able to reflect upon their past experiences, “at the time, I didn’t have any concerns for myself, my concerns were for him.” Family/friend caregivers acknowledge that emotional and financial burdens far outweigh the physical burdens, with the exception of older family/friend caregivers who find that the physical aspects of caring can be overwhelming at times. However, it is well understood that living in stressful situations can have long term physical impacts on the body due to prolonged exposure to elevated cortisol levels resulting in exacerbation of chronic conditions, depression, anxiety and other psychiatric diagnosis, and cardiovascular impacts such as hypertension, risk of heart attack, and stroke (31,32). Women were particularly susceptible to experiencing fatigue, depression, physiological symptoms associated with stress, and exacerbation of chronic disorders. Female spouses of people with ADRD found it especially challenging to care for husbands as the increasing dementia transitioned to needing greater physical aspects of care from women who were frequently physically smaller than their spouses.

For HCPs, the physical cost of caring was defined as the amount of work required to ‘rescue’ a family in crisis. Health care providers were frequently frustrated by the fact that families tended to wait until a crisis occurred before asking for help. The HCPs understood that providing respite care, accessing long-term care, and putting services in place rarely happens overnight. A number of HCPs recognized the need for additional education for family caregivers in understanding the significant physical toll caring for someone with memory loss can have. They felt that asking for help earlier in the process was critical so that when a crisis occurred services were already in place.

The physical costs of caring were approached differently by the family/friend caregivers and the health care providers. For many families the financial cost of asking and receiving services to help alleviate some of their burden was a significant barrier.

Financial cost of caring

Many family members referred in passing to both hidden and upfront financial costs of caring. One caregiver stated that “sometimes money becomes an issue and that kind of just blurs everything else.” The burden frequently fell on the shoulders of one informal caregiver, most often the primary caregiver:

It was financially at my expense...the gas was a high expense; it was half an hour to go get her and bring her back to my house for supper and then bring her back. That was twice a week and I think the hardest part was the lack of support from my siblings.

One caregiver chose to retire early because her mother with ADRD “was too much care, there was just so much care even though she was in a [long-term care facility].” For some, giving up work entirely had significant repercussions, “giving up my job meant giving up my salary so we were going to exist on just my husband’s salary because I was too young to collect any CPP.” Another caregiver recognized gaps in the system with respect to taking time off work and the impact it had on her quality of work as an educator:

She hadn’t died, so I couldn’t take five days off because of bereavement. I mean financially you can’t afford to say oh well, I’ll go a couple of months without pay coming in. I knew I wasn’t fully like giving my 100% in my day...I knew that my lesson plans were not top-notch like they had been.

Many of the informal caregivers we spoke to had negative opinions of the care provided in long-term care facilities. They made concerted efforts to provide or engage sufficient home-care to keep loved ones at home in an attempt to avoid long-term care facilities. However, many people either did not have the financial resources to cover such home-care costs or lived rurally, prohibiting access to satisfactory home-care of any kind. In some cases, when the family/friend caregiver made the decision to place their loved one in long-term care to ease the financial burden, they received backlash from family members, “he said [brother], that I stuck mom in a hole, in the dark, where she is going to die alone.”

Health care providers spoke of the desire for families to keep their loved ones at home. They also recognized that accessing resources and services in the community setting was not a simple process and that many families became overwhelmed by the levels of red-tape often gave up. Health care providers identified their role in needing to help families with navigating the bureaucracy of social services in their communities. However, every dimension of the cost of keeping the patient at home increases as the disease progresses and people living with ADRD become more dependent upon caregivers. HCPs recognize the value and importance of home-care but comment that there are a number of fundamental challenges with the home-care system. HCPs state that personal support workers are grossly under paid, under staffed, under trained, and under-appreciated. Home care workers are seen as a critical component of successfully keeping someone with ADRD at home for as long as possible. An HCP stated:

You’ve got these ladies you know, probably middle aged, need to work, working at minimum wage, doing very heavy...you know what I mean, so it’s hard to get good workers because...and not to say people aren’t good, but they’re just overwhelmed and there is no support for them either, right!

The cost of caring includes emotional, physical, and financial dimensions that slowly take a toll on the well-being of the caregivers. Recognizing the costs of caring can be the first step in addressing the challenges and putting sufficient resources and supports in place. With the right supports family members may be able to take a step back to view the whole picture as they come to terms with losing a loved one to ADRD.

DISCUSSION

The experiences of the family/friend caregivers and health care providers provided many interesting opportunities to improve our understanding of the cost of caring for family members with ADRD. The knowledge can guide our work to improve the outcomes for both the caregiver and the patient. We can address the stress of caring for someone with ADRD by providing intentional and targeted 'care' to the carer. We compiled recommendations that come from the interviews with both the HCPs and the family/friend caregivers. We believe that these recommendations may be helpful in improving a system of care that continues to experience demands for more and more services.

We found that women experienced feelings of burden, frustration and anxiety as a result of the caregiving role, especially when there was a history of discord between the patient and the caregiver, a phenomenon that is consistent with literature suggesting that the health of women who feel a sense of obligation to be caregivers is negatively affected (33,34). Women, especially the spouses and daughters of people with ADRD, were expected to take on the caregiving role. The caregiving role was particularly challenging as the ongoing deterioration in cognitive function in the care recipient was associated with both personal and role strain (35), especially when the caregiver is the spouse (36). The older the caregiver spouse the greater the challenges become as they begin to experience their own health related issues, increasing frailty, and subsequent difficulties with the caregiving role. For the older caregiver, it is important for the HCP to offer resources, such as a home care worker, to assist the caregiver. A crucial consideration for the health care provider is to introduce the HCW gradually into the care setting recognizing the disruption that the introduction of a stranger can have to someone living with ADRD.

Riffin et al., (37) found that women learning to assist with activities of daily living were more susceptible to caregiver burnout when caring for someone with ADRD than with other chronic conditions. Women were also more likely to be expected to take up the caregiving role without consideration of the toll on their families, careers, and other responsibilities. The women caregivers in our study highlighted the injustice of, and tendency to, elide the important aspects of their own lives by other family members. When compared with caregiving of other diagnosis such as cancer, HIV, or multiple sclerosis, Kim et al., (38) found that dementia and other cognitive impairments was most responsible for caregiver burnout as the patient slowly 'disappeared' before the caregivers' eyes. As women were expected to know how to care, they saw asking for help as a failure. Having someone come into the home, while a viable option to provide assistance and respite to the caregiver, was not openly accepted as it was seen as a negative comment on their ability and a potential attack on their pride in housekeeping. Health care providers need to pay attention to the needs of family/friend caregivers, being sensitive to when and what type of help is offered. Having a navigator role within the health care team can also help in managing the sometimes complicated process of finding resources in community.

Caregivers who waited until a crisis situation to allow home-care workers in the home found that the loved one became even more confused by the presence of the home-care worker. The HCPs suggested that home-care workers should be introduced into the home as a companion first and that with the development of a good relationship they may then be able to move into personal care with fewer objections from both the patient and the caregiver. Health care providers were adamant that the over-reliance on volunteer care providers was likely to cause greater problems in the future. Home-care workers who are appropriately trained and paid a living wage are a viable and necessary option for assisting families to stay together and to age-in-place. Greater resource allocation is needed to provide appropriate support to family/friend caregivers in a more organized and structured way. An HCP provided some insight into the value of home-care and the fact that it lacks formal support from the health care system.

"I think one of the biggest challenges are the home support services. For example, in my community we've got TOWN Outreach, which are the support workers that go into homes through Social Development to provide support, but often the support is not enough or not enough to keep them out of a nursing care home. So, we have a lot of patients that are kind of running down a slope where they are basically kept at home for a period of time, but once that two to four hours a day becomes not enough, we are often shipping people off to nursing homes, which is already a huge problem in the province with lack of access to nursing care beds. So, I definitely would say this is a very expensive and challenging service to provide, but home-care obviously is an ongoing way to keep people more comfortable and people often do better in their own homes than they do when they get into an institutionalized facility that is trying to be like a home, but realistically..."

Health care providers appreciate being able to rely on resources that support family/friend caregivers and services that contribute to decreasing the fatigue experienced by the family /friend caregiver. Health care provider support and services can alleviate caregiver stress (36,39). Care management by a multi-disciplinary team of health care providers has proven helpful in decreasing caregiver burden (40). Further to this, Zwingman et al. (40) stated that caregivers need to be provided with individualized packages of long-term care services that acknowledge the family's unique situation and specific needs, values, and desires. Our study found that formal caregivers who practice person and family-centered care recognize the unique situation of each caregiver and their loved one. It is critical to acknowledge the role of the ifamily/friend caregiver while keeping the patient at the center of the care relationship (11,16).

Other sources of support focus on multiple dimensions of the needs of the caregiver. The unpaid care, provided by family/friend caregivers should be recognized as essential to the sustainability of long-term care in the home setting (16). Cognitive behavioral therapy has also been recognized to help provide caregivers with an outlet for frustration, fear, and grief (41). Encouraging social relationships was vitally important to providing caregivers with a focus other than the unrelenting fatigue of providing care. When the costs of having a home-care worker in the home are covered by the patient's insurance plan or by the government, both the financial and emotional costs of caring are alleviated.

Family/friend caregivers should have access to respite care, have the opportunity to ask questions, and be encouraged to talk about their caregiver experiences. When this support is provided caregivers are less likely to resent the role of caregiving and more likely to have better quality of life indicators. As one HCP stated when discussing the importance of recognizing the stress of caregiving, "Because the one thing that will bring the tears to the eyes the fastest, is when I say to the caregivers, "when was the last time you got a complete night's sleep?"

Peer support was mentioned by both the HCPs and family/friend caregivers as an intriguing and valuable opportunity to connect with others. Myhre et al., (36) stated that caregivers provided with on-going education about the trajectory of the disease process were better able to handle the emotional and physical costs of caring. There were however, a number of barriers to being able to take advantage of peers and others who have experienced caring for someone with ADRD. Having someone to care for the patient while the caregiver attended educational sessions, being able to find transportation, and having sessions close to home were all identified as potential barriers that need to be addressed. Health care providers recognized the dangers of burn-out by family/friend caregivers and felt it important to link them with resources.

I believe that it's very important as a care provider to be able to have that discussion with family and to look at the future in the long-term. There's also a lot of ...guilt issues that go along with families, making promises that they can't keep, people... have caregiver's stress and all those issues and I feel quite comfortable in addressing those with my...you know, clients and their families. I really think that's very important.

LIMITATIONS

The cost of caring for family/friend caregivers manifests itself in three dimensions: emotional, physical and financial. There are many situations where it is difficult to tease these dimensions apart, especially when physical costs result in emotional costs such as burn-out, stress responses, and depression. Women are called upon to provide care more often than men with the expectation to provide care to a family member with ADRD. Women caregivers are particularly vulnerable to stress and burn-out, especially when the health care system fails to acknowledge the stress and costs of caring for a family member. Most caregiving situations have moments of tension, however with support, family/friend caregiving can provide satisfaction and personal growth (8,30). Health care providers can help alleviate some of this stress by working with both the family and the patient with ADRD to identify solutions and offer resources. In this situation, the family/friend caregiver needs to be recognized as the 'invisible second patient'. We will continue to see a rise in the number of people living in the community with ADRD, as such, we must prepare to support family/friend caregivers in whatever way is possible by engaging in patient/family centered care to address the needs of the family, as a whole.

CONCLUSION

The investigation into the experiences of health care providers and family/friend caregivers of people with ADRD uncovered some important points of

understanding. One limitation of the study is that we did not ask specifically about the quality of the relationship between caregivers and care recipients. It would be very helpful to gain a better understanding of the experiences of female family/friend caregivers who provide care whether through a sense of obligation or because they want to, and who have experienced some form of abuse from the care recipient. It would also be helpful to investigate the gap between how women experience caregiving relationships versus the societal pressures on women to provide care for their parents regardless of parent-child relationship history.

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