Title:

Informal caregivers' hopes and expectations of a referral to a memory clinic

Authors:

Debra Morgan[1]

Sheena Walls-Ingram[1]

Allison Cammer[1]

Megan E. O'Connell[1]

Margaret Crossley[1]

Vanina Dal Bello-Haas[2]

Dorothy Forbes[3]

Anthea Innes[4]

Andrew Kirk[1]

Norma Stewart[1]

[1]University of Saskatchewan

[2]McMaster University

[3]University of Alberta

[4]Bournemouth University Dementia Institute

Corresponding Author:

Debra Morgan
Canadian Centre for Health and Safety in Agriculture,
University of Saskatchewan
104 Clinic Place, PO Box 23, Saskatoon, SK Canada S7N 5E5

Telephone: (306) 966-7905
Facsimile: (306) 966-8799
E-mail: debra.morgan@usask.ca

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Abstract

Although only 20-50% of individuals with dementia are diagnosed, early diagnosis enables patients and families to access interventions and services, and plan for the future. The current study explored the experiences of rural family caregivers in the period leading up to a diagnostic assessment at a Canadian memory clinic, their hopes and expectations of the assessment, and their experiences in the six months following diagnosis. Using a longitudinal, retrospective and prospective qualitative research design, caregivers of 30 patients referred to the clinic were interviewed during the diagnostic assessment process and again six months after the diagnosis. Most caregivers reported first noticing symptoms two years prior to diagnosis. The pre-diagnostic interviews revealed a prevalent 'need to know' among caregivers that drove the help-seeking process. Caregivers hoped that the diagnosis would have the benefits of 'naming it,' 'accessing treatment,' knowing what to expect,' and 'receiving guidance.' When asked six months later about the impact of the diagnosis, the main theme was 'acceptance and moving forward.' Caregivers reported that the diagnosis provided 'relief,' 'validation,' and 'improved access to services.' These findings can inform care practices of primary health care providers who represent the first point of contact regarding expectations and experiences of dementia-related diagnoses.

Keywords: Canada; Saskatchewan; rural; dementia; memory clinic; caregivers; diagnosis

Dementia is a challenge for families worldwide, with an estimated 35.6 million people living with dementia in 2010 (Prince et al., 2013). A five-country survey revealed that 30% of respondents had someone in their family with a diagnosis of Alzheimer's Disease (AD) (Alzheimer Europe, 2011). In Canada, 7% of those over the age of 60 years and 49% over age 90 have dementia, and this prevalence is projected to increase by 2.3 times over the next 20 years (Alzheimer Society Canada, 2010). In Canada and internationally, rural areas are aging faster than urban areas (CIHI, 2011; NACRHHS, 2008), leading to high proportions of older people and thus more people at risk for dementia. Fewer than half of all dementia cases have documented diagnoses (WHO, 2012). For those diagnosed (only 25-50% in high income countries), dementia is detected too late for interventions to be beneficial (WHO, 2012). Without a diagnosis, people go without treatment, care, and organized support (Koch & Iliffe, 2010; Pratt et al., 2006; Prince et al, 2011).

Studies of the pathway to diagnosis of dementia have identified caregivers as crucial. Leung et al. (2011) found that caregivers initially encouraged patients to seek help, but over time actively pursued a diagnosis. Although shorter pathways to diagnosis occurred when caregivers recognized symptoms and sought help (Schrauf & Iris, 2011), attaining a diagnosis required considerable diligence by caregivers and marked delays were common (Teel & Carson, 2003). Time from first symptom recognition to diagnosis of dementia averaged 3.1 years, with delays occurring before and after seeing the first health professional (Speechley et al., 2008). In Ontario, caregivers identified the need for specialist services and more training of health care professionals to improve early assessment and diagnosis (Dupuis & Smale, 2004).

Patients and caregivers who live in rural areas experience additional barriers (Bradford et al., 2009), due in part to challenges of rural health delivery, including long distances, lower

population density, and widely dispersed populations (White, 2013). Indeed, a systematic review of factors contributing to missed and delayed diagnosis of dementia in rural settings identified problems related to providers, patients, caregivers, and the health system (Bradford et al., 2009). Access to diagnostic and post-diagnostic services is especially limited in rural areas, as is sufficient training of primary health care professionals to diagnose and manage dementia (Szymczynska, Innes, Mason, & Stark, 2011). A systematic review of informal caregiving in rural settings (Innes, Morgan, & Kosteniuk, 2010) found limited research on caregivers' experiences of dementia and insufficient information available to develop rural dementia care services that support the person with dementia and their family caregivers. Therefore, the purpose of this study was to explore for the first time the experiences of rural informal caregivers in the period leading up to a diagnostic assessment at a memory clinic, their hopes and expectations of the assessment, and their experiences in the six months following assessment and diagnosis.

Methods

This study used a longitudinal, retrospective and prospective qualitative research design in which in-depth interviews were conducted at baseline assessment and six months later. Data were collected between 2010 and 2012. Ethical approval was granted from the University of Saskatchewan Behavioral Research Ethics Board.

Setting. The Rural and Remote Memory Clinic (RRMC) is a research and publicly funded clinical centre located in the city of Saskatoon (population 236,000) in the mid-western Canadian province of Saskatchewan (population 1,072,082, area 651,035 km^2, population/km^2 1.88) (Government of Saskatchewan, July 2012). Saskatchewan 2011 census data show a higher proportion of seniors (>65 years) living in smaller centers (towns 21.3%; villages 20.1%, and recreational villages 25.8%) compared to cities (14.0%) (Elliot, 2012). With a higher prevalence

of dementia with advancing age (Prince et al., 2013), rural communities have a higher proportion of people at risk of developing dementia, yet less access to needed supports and services.

The RRMC involves the patient's family caregivers at all stages, including a pre-assessment via telehealth videoconference in the patient's community. Caregivers later accompany the patient to the full day in-person diagnostic assessment at the RRMC, located in a tertiary teaching hospital. The clinic visit ends with a feedback meeting where the patient and accompanying caregivers meet with the clinical team to discuss the patient's diagnosis and their recommendations regarding treatment and referrals to support services. Follow-up appointments are conducted via telehealth videoconferencing at six weeks, 12 weeks, six months, and as needed. At one year and annually thereafter, patients are assessed by the full team at in-person follow-up appointments. Details about the assessment protocol and use of telehealth are reported elsewhere (Morgan et al., 2009; Morgan et al., 2011).

Data Collection. Over eight non-consecutive months between 2010 and 2011, a convenience sample of all family members (termed "caregivers" in this paper) who accompanied patients to the full-day assessment at the RRMC was invited to participate in a semi-structured interview. We also sought permission to contact them for prospective follow-up interviews after six months via telephone. Caregivers were informed at each point of contact that they had the opportunity to discontinue participation. At clinic day, after reviewing and signing consent forms, they were interviewed in a private room while the patient completed part of an individualized assessment elsewhere. The interviews took place a few hours prior to the end of day team conference and subsequent feedback session. Patients were engaged in an interdisciplinary assessment that required the full day and therefore they were not available to participate in these interviews. Guiding questions for the clinic day and 6-month interview are shown in Table 1.

--Insert Table 1 about here--

The RRMC operates one day per week, and typically sees six new patients per month. Five consecutive months of caregiver interviewing were followed by a 3-month pause to allow for transcription, initial analysis, and modification of the guiding questions. All interviews were audio recorded, transcribed, and checked for accuracy. Data collection then continued for 2 months, followed by an analysis period and a final month of recruitment, after which the researchers agreed that the saturation point had been reached and no new themes were being generated. On average, initial interviews were completed in 25 minutes and 6-month interviews in 20 minutes.

Data Analysis. Data analysis employed a constant comparative approach (Charmaz, 2006). NVivo software was used to store coded data and facilitate retrieval of data. Open coding was carried out through line-by-line coding, with an attempt to capture all active categories. To refine conceptual codes, the data were then re-read, keeping in mind the question: "what is happening here" (Charmaz, 2006). This process was followed by focused coding to condense and compare data across interviews. Memos that were written on first and subsequent reads were revisited and incorporated into the analysis. Finally, a core category was determined, which represents the principle theme of the data. Several strategies were used to ensure analytic rigor (Shenton, 2004). The interviewer (SWI) and principal investigator (DM) met weekly for debriefing sessions, to determine coding schemes, interpret data, and refine the interview guide when analysis revealed areas that required further exploration. Poster presentations of early findings at scientific conferences provided opportunities for dialogue with peers and helped develop the analysis. Because caregivers were contacted at two points in time, we were able to explore individual's stories in-depth, ensuring more accurate representation and enhancing

credibility, confirmability, and dependability of the findings (Shenton, 2004). We documented the analysis process to create an audit trail, used memos to record analytic notes, and have attempted to provide enough description of the study context to allow others to determine the degree of transferability to other settings.

Participants. Initial interviews involved 46 caregivers, who were caring for 30 patients. Seventeen interviews were conducted with a single caregiver, 13 with two caregivers, and one with three caregivers. Caregivers (15 male, 31 female) included wives (n = 10), husbands (n = 6), daughters (n = 15), daughters-in-law (n = 2), sons (n = 5), other relatives (n = 7), and friend (n = 1). Forty-one percent of caregivers interviewed at baseline lived with the patient. Patient diagnoses were Alzheimer's Disease dementia (AD, n =15), mild cognitive impairment (MCI, n = 4), frontotemporal dementia (FTD, n = 3), vascular cognitive impairment, no dementia (VCI, n = 1), no cognitive impairment (n = 5), and inconclusive (n = 2). At 6 months, 33 of the original 46 caregivers agreed to participate in the second interview via telephone, and these 33 cared for 26 patients. Reasons for attrition included: deferred to the other (typically primary) caregiver (n = 5), lack of interest (n = 2); unreachable (n = 2); researcher calling made patient anxious (n = 2); and patient inappropriate for the study (n = 2).

Findings

Although four caregivers noticed symptoms less than one year prior to the assessment, for the majority of patients (20/30) their caregivers reported first noticing symptoms two years earlier, with the remaining caregivers reporting three to five years. This period included wait times for the RRMC, which averaged 11 months. Most patients were referred by their primary care provider, although one patient with FTD was referred by a specialist for a second opinion.

Five patients were taking Aricept (an acetylcholinesterase inhibitor) at initial assessment, but none of their caregivers recalled having been given a diagnosis.

Clinic Day Interviews. The experiences of caregivers during the time between noticing symptoms and being seen in the clinic varied. Seven caregivers described experiencing extreme distress, primarily due to patient safety concerns, but in several cases caregivers were experiencing deteriorating physical and mental health. At the other end of the spectrum, caregivers were less distressed, but still anxious to get answers. A third of the caregivers indicated that there was a particular incident that triggered help-seeking.

> What happened was we went to the lake last summer and we noticed Mom's having less interest in things, couldn't remember things. There had been an incident in [previous year] where she had seen these "little people" that was quite distressing to her. (son)

> What we are afraid of is she's going to leave the stove on and maybe catch something on fire. Like OK, she tried to bake something for Thanksgiving and she called over here and she said I can't get my stove turned on and it stinks so bad. And so [we] run down there and she had her oven up to 700 degrees. (daughter)

> Mom had another little near mishap driving this winter. Uh, she pulled out in front of a gentleman with a loaded pick-up truck and he thought he was going to kill her, and he still doesn't know how he missed her. (daughter)

Many caregivers reported that they could not leave their family member alone, which led to isolation, loneliness, and loss of freedom.

> It's different. We can't do what we usually do, or if we wanted to go to the lake we can't go to the lake, 'cause if we go fishing the hills are too steep for her, or there's all kinds of things. It's got positives I guess and negatives. (son)

> I can't go away on week-ends or anything like that. If I go away for the day I usually take her but I hardly even like go down to [nearby city] to shop or anything like that. I rarely do that anymore 'cause I just don't want to leave her. And when she does come, it's harder for me to do anything like that with her because she has to be right beside me…so yeah, it's hindered. (daughter)

Caregivers who did not live near the patient described the challenges of being at a distance.

> Well, people would phone me and tell me this is what's happening. You need to do something. You need to do something. And when I talked to my mom on the phone she was fine…. And I thought that they were just, you know, not being very kind. It took me awhile to understand that yes, there was in fact something wrong. And because I lived so far away-- it takes over two hours to get to her house from where I live-- I don't go out [there] a lot… I didn't realize it was the way people had said it was. And they would know. They're there, I wasn't. (daughter)

Some caregivers reported feeling anxious and frustrated about having to wait for the clinic appointment, especially when they saw a decline in the patient's condition, whereas others were more resigned to waiting for specialist appointments.

> The only time it really bothered me is when I noticed things getting a little bit worse and I'm thinking, okay, when is this going to happen? We need to get this checked out, because every other test they did on her for every other possible reason she could be having this memory issue, they all came out just fine. So this was kind of our last resort for answers. So yeah, I was getting a little anxious. (husband)

> I would say it's been mostly, well, it's always in the back of our minds, but you know when you don't live there, and we're not affected by the day-to-day stuff. Certainly it was of concern to Mom [patient's wife]… so when I phoned to let them know there was a cancelation… well she was very receptive. (son)

Caregivers who reported supportive family relationships and shared responsibility for caregiving appeared to be less distressed, whereas those who described non-support from other family described this situation as stressful and frustrating.

> I think it's been happening for, well at least five years noticeably for myself, but its definitely been a process because my one sister has—she's seen it, but it's taken her awhile to see it also, but my brother has just refused to deal with it on any level until just this last month. (daughter)

Many caregivers described the need to "do something" to help the patient and get a better understanding of what was happening. After pushing for the clinic appointment for his wife, one husband stated "but at least I feel satisfied that I'm doing something—or trying to do something." Another husband stated "We had a chance to be here today and [our son] made a phone call and

got in here and hopefully we do *something*, find *something."* The following quote also illustrates caregivers' need to do something to help the patient.

> If there's something happening I want to seek it out. I don't want to wait until she has really changed and she's different and people are saying something.… if there's a concern then let's look at it. That's why we're here today. (husband)

During initial interviews, half of the caregivers reported that the process of help-seeking for their relative had been stalled at the point of the primary care provider. This experience of "getting stuck" occurred when their attempts to have their concerns taken seriously were unsuccessful. "Taking charge" describes caregivers' actions aimed at keeping the help-seeking process moving, by calling, writing, or making an appointment with the patient's physician.

> I went for how many years now I've been mentioning it [to the Doctor] that I've noticed … mentioning about her memory and they did these kind of little tests or something and asked her like, what date it was … and he would say well he didn't really see any, uh, difference. And only last year he finally, he would refer us. (daughter)

> So then more time went by and then our youngest daughter she said what's happening with that test for Mom's memory? Well I said I don't know, she's been going to the doctor and we don't seem to be getting anywhere. Well she says I think we'd better start seeing what's happening. (husband)

The Need to Know. The driving force behind the process of seeking assessment was caregivers' 'need to know,' which had the following properties: 'Naming It,' 'Accessing treatment,' 'Knowing what to expect,' and 'Receiving guidance.'

Naming it. By knowing the diagnosis, caregivers could more easily begin to "deal with it" themselves and to seek help from others. Caregivers said that naming the problem would enable them to move forward both psychologically and in practical terms.

> Then you can deal with it. You're putting a name to it. You know what it is and then you can get on with it instead of wondering what's the problem. (wife)

> Sometimes it is better to know than not know. It was the same with my husband's cancer. Like once you know, you can deal with it. And this will be the same way. It seems like

> nowadays things have to be labeled. And once there's a label of Alzheimer's for my mom, then we can go forth. (daughter)

Not understanding the cause of the changes in the patient was upsetting for caregivers, who wanted an explanation for what was happening. The uncertainty of not knowing motivated them to seek help.

> Well, a better understanding of exactly what it is, like what her condition is, like exactly what it is. I haven't really been told from any doctor or anything, but we know there's something about her memory, but I just don't know what it is, I don't know if it's dementia. (daughter)

> Just to have a reason for his change… you have a person go from day to night, uh, just to know… what caused it would help… it doesn't change the outcome at all but it just feels, it would be a help I think. (wife)

Accessing medication treatment. Expectations about medication treatment for a diagnosable condition were a clear component of the 'need to know,' and may have even been important in maintaining caregivers' help-seeking behavior. In fact, most caregivers expressed hope that there would be a treatment available once the diagnosis was made. Some were aware that medications may help slow the progression of the dementia whereas others believed that there must be an effective medication because "there is a pill for everything."

> I heard about a medication that can be taken to slow the process - not stop it - but it would slow the process so we were trying to get him in here… So I wanted [an assessment] to happen quicker. (wife)

> Well I'd like to think there's a medication that would help her. It helps everything else. It certainly is not going to help her a year or two down the road, it's not going to, it's too late. I'm hopeful that maybe there will be yet. (husband)

Knowing what to expect. Most caregivers expressed the desire to know what the diagnosis was, what symptoms to expect as the disease progressed, and how quickly or slowly the decline might be. Caregivers want to know "what it is" so that they could begin to "deal with it." Knowing the nature of the problem was a prerequisite for taking control of the situation.

> More understanding, some kind of support, more of what I can expect… because I don't really know. You know, I don't know how long this is gonna carry out, you know? (daughter)

> It just seems like that last couple of years I have been trying to sort of find out, or just even to have somebody say 'no, this is what it is, this is what it's gonna be and it might progress to this.' (wife)

Having a timeline for the progression of the symptoms was seen as reducing some of the uncertainty in the situation and enabling them to start planning for the future.

> To know that this is what it is and this is how it's going to progress and then we'll have to deal with it…. (wife)

> Potentially knowing whether this is going to worsen or whether it has the ability to get better, or whether it may just stay the same you know, like knowing what's causing it will at least give us some insight into what the future might look like, so that we can make better arrangements and plans with that in mind. (daughter)

Receiving guidance. Caregivers wanted support in making decisions about issues such as ability of the patient to live alone and their decision-making capacity, and to know that the clinic team would be there if they needed help and advice in the future.

> And at what point do you have to put her in long-term care or something? Yeah, so I guess more information and a little bit of guidance. (daughter)

> Being here is helpful because we'll get more information about where she's at and then from there I'll be able to make better decisions… I'm looking [for] whatever else anyone can provide for me because I don't want to make the wrong decision. Because this is it. Like I can't—I have to do the right thing. (daughter)

Many caregivers were postponing making major decisions affecting the patient until they had more information. They struggled with balancing the patient's independence and protecting them from financial and safety-related problems.

> We would like answers, we'd like to know, like is she capable of making good decisions, good judgments? Is she able to do that? We don't know. Sometimes we think yes then the next time 'oh, we've got to do something. We've got to intervene.' And we don't know where to begin. And is it bad?... Or is there something that is fixable. (daughter)

> And what I'm hoping for is some prognosis stuff… I have some concerns about her ability in terms of finances… Dad had told my sister she had a significant amount of money in her chequing account and it's about that decision-making… is she able to manage money? (daughter)

The impact of knowing at six months

Six months post-diagnosis, caregivers displayed a reduced sense of urgency and stress compared to the initial interviews, regardless of the diagnosis. Receiving a diagnosis seemed to be the climax of their help-seeking process. Caregivers were interviewed just prior to receiving the diagnosis on clinic day, and then six months later; consequently, we did not capture their immediate reaction to the diagnosis, which may have changed over time. At six months, acceptance of the diagnosis and moving forward was the core category of the impact of knowing. Properties of this category were 'relief,' 'validation,' and 'access to support and services.'

Acceptance and moving forward. Receiving a diagnosis helped caregivers accept the new reality and move forward. Caregivers could begin to plan for care and adapt in cases where their family members were diagnosed with a dementia, or for those who were not, in the knowledge that dementia was not an immediate concern. Understanding symptoms and being able to name the problem helped some caregivers come to a place of acceptance. Talking to the clinic team about their questions and concerns also helped them move forward. The wife of a patient diagnosed with frontotemporal dementia reflected on how the explanation of her husband's symptoms made things easier to deal with and accept:

> After the [clinic] trip… I could tell myself that I understood more the reason for why things were going on…. Because until you know the reason, you just think it's bad behavior. It was very helpful… because I was getting cross, you know? Like why are you laying around all day? Well as soon as I had an explanation for it… then I was less liable to feel frustrated by it. (wife)

Some caregivers in this study retrospectively reported experiencing something akin to denial about their relative's potential dementia. They saw the signs and logically knew that

dementia might be a possibility but this reality was too upsetting to them. The diagnosis helped some caregivers to begin accepting the situation:

> I guess… I had a hard time accepting it [but] I've heard it from her doctor, I've heard it from the doctors here in [place of residence], and I've heard it now from the Memory Clinic. So it's confirmed. (daughter)

Having a name for their family members' condition allowed caregivers to help others understand the patients' behaviors or symptoms. This wife of a patient diagnosed with frontotemporal dementia used her husband's diagnosis as a tool to combat stigma and accept his impairments:

> Even people in church and people will stop me on the street and say you know like how's [patient] doing? Because like they see him and he just seems like, and I, I tell them. I mean what, there's no, no secret. There's no shame in it. It's just what it is, you know? (wife)

To a lesser degree, caregivers reported that a diagnosis of a dementia helped the patient accept his or her illness and circumstances. Caregivers often spoke as though they represented their entire close family, including the patient in their responses.

> We did get some satisfaction out of going [to the Clinic], and talking to the people who were there… and the things that they recommended to do, and that's how we accepted it. (husband)

> I think he was pretty pretty down on himself and really frustrated at first, but like now he's kind of adapting a little bit more… using notes and stuff and it just seems like he's maybe come to terms with it for one thing. (son)

Relief. The pre-diagnostic stage was characterized for caregivers by anxiety and speculation about the cause of the patient's symptoms. Caregivers were relieved for themselves and the patient when receiving a non-dementia diagnosis. The wife of a patient diagnosed with vascular cognitive impairment described their reaction to his diagnosis:

> *He was really quite concerned and he was happy that his diagnosis wasn't… Alzheimer's at this time… they found a few things that …they were going to watch but he wasn't actually diagnosed with it." (wife).*

Spouses of patients who were diagnosed as 'no cognitive impairment' said they were relieved for the patient who had been concerned.

> I didn't really think that he had any dementia when he went it. He had that concern… so I was relieved on his part that he didn't have it, because I know he was worried about that hitting early in life. (wife)

Many caregivers also reported a sense of relief in just getting an answer, regardless of the actual diagnosis. The daughter of a patient diagnosed with AD described the impact of knowing her mother's diagnosis:

> …it just gives a person the peace of mind that yeah, we definitely know what it is and life goes on, I guess. (daughter)

Access to support and services. A tangible benefit of receiving a diagnosis was that it introduced caregivers to support that they were previously unaware of. An example is the First Link program offered by the provincial Alzheimer Society, where staff contacts the family a few weeks post-diagnosis to offer support and information. Some caregivers reported that a formal diagnosis from the RRMC facilitated linkages or was an impetus to connect with community services such as Home Care.

> It gave us something concrete… so that we can let the [local primary health] clinic know and with Home Care… get some help through that way for my mother especially because she's with [the patient] 24 hours a day. (daughter)

> …before we went to [RRMC] we didn't know that Home Care would assist us, that they were …available to assist families in that kind of situation. (niece)

As a result of the diagnosis, one caregiver attended an Alzheimer Society program for caregivers, which helped her in caring for her husband:

> Yeah, it has [helped]. You know it seems like I'm getting stronger every day I have to deal with him and that. And I knew even before these classes that… you know I have to have patience with him. (wife)

For another caregiver, a diagnosis prompted discussion and planning with his wife's family doctor about the possibility of long-term care placement in the future. This might not have otherwise occurred:

> Oh, yeah, well, the doctor knows all about it eh? So she said, when it gets too hard for you, that you couldn't handle it, then we can get her in there. We won't have no problems, she said, 'cause I think those people get pushed ahead of the others a little because [of a dementia diagnosis]. (husband)

Validation. Caregivers in this study identified the psychological benefit of having a concrete name for the symptoms they had been witnessing in their family member. In early stages of their relative's memory loss, many caregivers questioned whether symptoms were 'normal aging' or something more serious. Having their experiences validated helped them to accept the diagnosis made at the clinic and to move forward. The wife of a patient with a long history of memory problems described the experience of living with someone with dementia and the benefit of having that experience validated:

> I guess maybe unless you live with a person day in day out… other people, they wouldn't see it like I would see it. And I guess just having you guys [RRMC Care team] say… you're not alone in that, and what you are saying is correct'… it made a difference. Then you can carry on without being frustrated. (wife)

Having the care team agree upon a diagnosis of dementia validated for some caregivers that their perceptions and concerns during the pre-diagnostic phase were legitimate.

> Well we got a diagnosis which is what we really wanted because it kind of reinforced that yes, we have a problem. The team was really helpful in terms of supporting us in where we were coming from. (daughter)

> [What has changed] is probably just myself… I think just having you guys just explain stuff in-depth has kind of made a difference for me. I guess it put into words what I was feeling and how I'd seen things, and just I guess letting me know that it was as I was seeing it and that it was normal for [his condition]. (wife)

The daughters of a patient diagnosed with MCI, who had clear expectations that the assessment would reveal their mother suffered from AD because of a family history, were

disappointed with the diagnosis. They perceived MCI to be a 'lack' of a diagnosis. The absence of the diagnosis they expected meant they could not have their experiences validated and feel confident in moving forward with pursuing services such as respite or home care. This dissatisfaction was not observed among caregivers in the other three cases of MCI among our participants, who did not have an expectation of a specific diagnosis.

Discussion

While some caregivers reported a "smooth pathway" to diagnosis, many others reported a difficult and complex journey to achieve a diagnosis for their family member. Their experiences were more like the "fragmented" and "dead-end" pathways described by Hinton et al. (2004). By the time caregivers and patients in our study arrived at the clinic, it had typically been approximately two years since they first noticed signs and symptoms of cognitive difficulties in their family member, similar to the delays described in other studies (Knopman, Donohue, & Gutterman, 2000; Speechley et al., 2008). The similarity in delays across these studies is interesting, given our rural sample, but future research comparing urban versus rural help seeking processes are required. Caregivers are reported elsewhere to have experienced difficulty and delay in accessing diagnostic assessment, due to a dismissive response to their initial concerns by their primary care physician (Robinson et al., 2009; Teel & Carlson, 2003). As in other studies, caregivers often played a key role in keeping the help-seeking pathway moving after encountering obstacles (Leung et al., 2011). The uncertainty about what was happening and what they should do about it created a feeling of being in limbo and motivated caregivers to push for a diagnosis. Some of our caregivers may have been motivated based on specific incidents, either unambiguous evidence of lost abilities or behaviours that were of concern for safety reasons. Whatever motivated these rural caregivers to seek a diagnosis, our data are consistent with other

studies who have reported caregivers' need to be "diligent" (Teel & Carson, 2003), "proactive," (Hinton et al., 2004), and "insistent" (Leung et al., 2011) with the patient's primary care physician.

As Prince et al. (2011) state, underdetection of dementia is a complex phenomenon with no simple solutions. The findings of this study have implications for patients and caregivers, health care providers, and the health system. Knopman et al. (2000) found that 60% of families did not receive a diagnosis of AD from the first physician seen, most often a primary care physician. Our data suggest families wait to access treatments and plan for the future based on a diagnosis. For this reason alone, under-diagnosis of dementia is a major healthcare challenge. Moreover, these data are consistent with findings that seeking a diagnosis is clearly a family-initiated activity. Our data suggest that patients and caregivers should be aware that they may need to be proactive in their interactions with health care providers. Better public awareness of the early signs and symptoms of dementia and the value of a diagnosis and available resources are needed to support early recognition and help-seeking by families (Speechly et al., 2008; Koch & Iliffe, 2010).

Since patients almost always seek help first from their primary care physician, primary care has been identified as an important focus for improving early detection (Löppönen et al., 2003). Reviews of barriers to diagnosis have identified multiple physician-related factors (Bradford et al., 2009; Kock & Iliffe, 2010) including lack of support, time constraints, diagnostic uncertainty, difficulties in disclosing the diagnosis, and belief that diagnosis is not worthwhile because of lack of treatments or benefits. Because of the small number of incident dementia cases encountered by any one physician in primary care, it has been argued that experience alone is not enough and must be supported by educational strategies aimed at

changing clinical practice (Koch & Iliffe, 2010). While some countries have developed policies that diagnosis should be made by specialists (e.g., UK Department of Health, 2009) the lack of specialists in rural settings makes this approach unrealistic for routine diagnosis. Improving detection, diagnosis, and management of dementia in rural settings will be dependent on enhancing the skills and supports available to rural primary care providers. As suggested by others, a team-based approach to care, based on chronic disease management principles (Leung et al., 2011; Alzheimer Society of Canada, 2010) would provide support to primary care physicians and improve the quality of diagnostic and post-diagnostic support to patients and families.

Perhaps the main finding from this study is the perceived benefits of a diagnosis, which support the recommendations for early diagnosis and disclosure (Prince et al., 2011). Relief about a non-dementia diagnosis may appear intuitive, but for families where the diagnosis was a form of dementia, most previously suspected this, and wanted to end the speculation and move forward. As noted by Speechly et al. (2008) acknowledgement by a health care professional that there is a problem, even if there is uncertainty about the diagnosis in the early stages of the diagnostic journey, may allow families earlier access to resources and information. In a systematic review of literature focusing on spouses where one partner is diagnosed with a cognitive impairment, Prakke (2011) also found that a diagnosis provided explanation and legitimization by merely naming the problem. For most of our caregivers, the process of seeking and receiving a diagnosis was in itself an intervention; it provided validation and opened doors to services.

Another main finding in this study pertains to the expectations of caregivers in this study regarding access to treatment, which align with those of Cahill and colleagues (2008) who found that one third regarded treatment as an expectation of coming to a memory clinic. These data

suggest that expectations for a medication treatment are a key component of why caregivers seek a diagnosis for their family member. The expectation of medication-based treatment could be problematic: for many types of dementia medications are not indicated, and they are not indicated for MCI. Clearly increased public awareness about the benefits and limitations of medications for dementia are needed, and clinicians working with families seeking diagnoses need to be aware that families may have high expectations for a medication based treatment.

Regardless of whether medication treatment was indicated or not, six months after the RRMC assessment, many caregivers reported benefits of getting a diagnosis, particularly having coming to a place of acceptance and moving forward with their lives, but also relief, validation, and greater awareness of resources and services. Similar findings were reported in a study of benefits of a diagnosis, including confirmation of a medical condition, access to treatment, and help preparing for the caregiver role (Wackerbarth & Johnson, 2002). Future research on expectations for medication treatment, access to treatment based on form of dementia diagnosed, and satisfaction with the diagnostic process is needed since it appears that caregivers view access to treatment, in all forms, as a benefit to diagnostic help-seeking.

Finally, for many caregivers, the diagnosis provided information on prognosis. In a survey regarding the information needs of the relatives of persons with dementia, 41% responded that they wanted information on prognosis (Thompsell & Lovestone, 2002). In some cases, such as MCI, prognosis is less clear and is dependent on sub-type (e.g., amnestic MCI has a higher risk of conversion to dementia than non-amnestic MCI) (Espinosa et al., 2013). Bleiszner and colleagues (2007) found that couples for whom one partner had been diagnosed with MCI found the uncertainty of the diagnosis to be confusing and anxiety-provoking. This finding was echoed by the two daughters in this study who perceived the diagnosis of MCI to be inconclusive and

unhelpful, whereas other caregivers of patients with MCI diagnoses reported that both they and the patient were relieved. Although a minority view, this negative case example could be seen as supporting the need for information on prognosis. MCI is presented as a diagnosis where 'what to expect' is unknown, and close follow-up is required. It is plausible that the families for whom the MCI diagnosis was viewed positively were simply relieved their family member was not diagnosed with some form of dementia, and they were content with not knowing the prognosis. Although only four caregivers of MCI patients were included in the sample for this study, findings suggest that future research is needed to determine the meaning of this diagnosis to caregivers and patients.

Limitations

Given the importance of patients' experiences in the dementia journey, a limitation of this study is the exclusive focus on caregivers' perspectives. Future research is clearly needed to determine the experience of patients in the diagnostic help-seeking process, assessment process, and the meaning of the communicated diagnosis for them. The current study used a convenience sampling method and is a mixed sample in terms of type of dementia and caregiver-patient relationship. However, the fact that none of the caregivers refused an initial interview suggests we are not merely presenting the experiences of those who are most comfortable sharing their story. A further limitation of the study is the fact that the sample is taken from a memory clinic population, and may not reflect the experiences of caregivers accessing care in a general practice setting. Moreover, the rural nature of this sample may have influenced the diagnostic help-seeking process, or made this sample more selective. Some caregivers requested the referral from the patient's primary care physician, and therefore might represent those who are particularly assertive or motivated to attain a diagnosis. Despite the variety of circumstances among

caregivers, we argue that these findings may be transferable to those who seek and attain a referral to a memory clinic, within the first six months following diagnosis, and those who are involved as much in the patient's life as to accompany them to an out-of-town day-long clinic assessment.

Conclusion

The absence of a timely diagnosis for dementia can have deleterious effects on the emotional well-being of patients and caregivers and can create a missed opportunity to obtain therapeutic treatments and access to support services (Prince et al., 2011; WHO, 2012). This study highlights the value that a sought-after diagnosis can bring about in the lives of caregivers and patients. These benefits may not always be obvious to care practitioners. Physicians and other primary healthcare providers need to be aware of the psychosocial benefits of receiving a diagnosis for family caregivers, who provide the majority of unpaid care for persons with dementia. We hope that the findings of this study heighten awareness among primary healthcare providers of potential ways caregivers can benefit from a timely diagnosis.

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Research Highlights:

- Families reported ‘getting stuck’ and having to ‘take charge’ in the process of seeking an assessment for memory concerns.
- Caregivers’ ‘need to know’ drove the help-seeking process. Caregivers expected a diagnosis would have the benefits of ‘naming it,’ ‘accessing treatment,’ ‘knowing what to expect,’ and ‘receiving guidance.’
- Six months following diagnosis, the main theme was ‘acceptance and moving forward.’ Caregivers reported that the diagnosis brought relief, validation, and improved access to services.