Self-Management of Dementia

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RESEARCH REPORT

Self-management of chronic disease is becoming more common as an approach to chronic disease prevention and management. However, self-management has typically been focused on chronic diseases such as cancer, arthritis, and diabetes. Self-management of dementia is only starting to emerge as a focus of discussion (Bahrer-Kohler, 2009; Mountain, 2006). "The commonly held view that people with dementia cannot learn new skills and therefore any intervention will at best fail and at worst have an adverse effect upon the person and their carer, is now being challenged" (Mountain, 2006, p. 434). Given the predictions of incidences of dementia by the Rising Tide study (Alzheimer Society of Canada, 2010), self-management of dementia is necessary if we are to cope with the increases in dementia and ensure quality of life for persons with dementia and their partners in care.

The concept of self-management of chronic disease refers to the ability of individuals to protect and promote health through various activities and the organization of daily life (Bahrer-Kohler & Krebs-Roubicek, 2009). Lorig (1993) suggests that self-management is "…learning and practicing the skills necessary to carry on an active and emotionally satisfying life in the face of a chronic condition" (P. 11). Self-management can be viewed in two different ways: (1) changing lifestyle so that patients and caregivers are actively involved in analyzing the state of problems and concentrating on therapy; or (2) as proactive self-management in managing situations on a day-to-day basis (Bahrer-Kohler & Krebs-Roubicek, 2009). The role of patients, then, is changed from a recipient of care to an active partner (Bahrer-Kohler & Krebs-Roubicek, 2009). Self-management programs should focus change on three levels: "1) at the level of the patient to improve information provision and knowledge; 2) at the level of the professional, to direct their responses towards a more flexible, patient-centred approach; and 3) at the service level, to improve access to services" (Mountain, 2006, p. 431). As the focus in dementia research has often been the causes and treatment, the day-to-day experiences of living and coping with the disease continue to emerge as important issues (Cotrell & Schultz, 1993; Mountain, 2006). Empowering patients "...by providing information, skills and techniques to improve self-care and doctor-patient interaction" (Bahrer-Kohler, Krebs-Roubicek, & Ephraim-Oluwanuga, 2009, p. 81) can improve the quality of life of people living with dementia and their partners in care.

Research Purpose and Questions

The purpose of this research was to explore the meanings of self-management from various perspectives—people with dementia, partners in care, and health service providers. The specific research questions were as follows:

- To explore the meanings and definitions of self-management from various perspectives and experiences with self-management;
- To explore the opportunities, benefits, challenges and constraints to self-management of dementia
- To explore the components of self-management from various groups' perspectives;
- To further understand what factors might support self-management of dementia;
- To explore what resources currently exist to support self-management of dementia; and
- To explore the structures of the health care system that support self-management of dementia.

Methodology

Two sources of data were collected—open-ended on-line questionnaires and interviews. We describe the data collection based on each source below.

Open-ended On-line Questionnaire
An open-ended on-line questionnaire was developed and hosted through SurveyMonkey. This questionnaire was specifically geared toward health service providers. The intent of this questionnaire was to gain preliminary information on how health service providers were thinking about self-management in broad terms, and how applicable the concept was to the dementia context. An invitation to participate in the survey was sent by email through a number of methods. Health service providers were given a brief explanation of the study and were invited to participate by clicking on the link in the email which would bring them to the questionnaire. The email invitation was sent out through the research centres' email lists and other partnering organizations. Because the email invitations didn't come through a central email but came from each centre, it was somewhat difficult to calculate the total number of invitations that were sent out. However, we anticipate that approximately 1,000 email invitations were sent out. A reminder email was sent out approximately 3 weeks after the original email was sent. We received 90 responses to the questionnaire.

The questionnaire asked the following questions:
1. In a few words, what does self-management mean to you?
2. Are you familiar with self-management models? If yes, which ones?
3. In your opinion, what are the most important ingredients for successful self-management?
4. Do you think self-management of dementia is feasible? If yes, why? If no, why not?
5. In your opinion, what would be the most important ingredients for a self-management model of dementia?

The questionnaire then asked professional information about how participants would describe their profession, what health care setting they worked in, and if they worked with populations with chronic disease or dementia. Finally, participants were given the opportunity to provide any further comments.

The surveys were downloaded from SurveyMonkey, and analyzed by hand. A research assistant read through the surveys and thematically grouped the responses in each question. A code was assigned to each response so we could conduct some numeric analyses on the data. While we are not able to conduct inferential statistics on this data, we are able to present basic descriptive data in the next section. Because the open-ended questions were thematically coded and then analyzed numerically, data findings should be interpreted understanding that these categories represent broad views of participants. This data does provide an overall glimpse of the characteristics of self-management from participants' perspectives, as well as important information to construct a more comprehensive survey in the future examining issues of self-management in the dementia context.

Interviews and Group Interviews
Interviews, both individually and in groups, were conducted in addition to the open-ended questionnaire. These interviews were focused on various groups, including people living

with dementia, partners in care or family members, and health service providers. Individuals were recruited through various means. First, people with dementia were recruited through local Alzheimer chapters and through the research centres. In total, 17 people living with dementia participated in group or individual interviews. Additionally, partners in care were recruited through the same means, and nine partners in care participated. Some of these individuals participated with a person with dementia, while others did not. Finally, health service providers were invited to participate in an interview. These people were recruited through the open-ended questionnaire as well as through the community consultation. In total, fourteen health service providers participated in an interview.

The interviews were conducted in people's homes, workplaces, and over the phone. In total, 40 individuals participated in interviews. The interviews covered questions such as people's backgrounds, the perceived meanings of self-management, the applicability of self-management in the context of dementia, the challenges and opportunities, and current and potential resources to support self-management, including health care system structures.

The data was transcribed by an external transcriptionist. It was then entered into NVivo and analyzed by the PI and a research assistant. First, the data was read through numerous times to gain familiarity with the data. The interviews and focus groups were then transcribed and coded thematically. Coding is the process of analyzing data (Strauss & Corbin, 1990). First cycle coding occurs during the initial coding of the data, and structural coding as a type of first cycle coding was used (Saldana, 2009). Structural coding refers to applying a content-based or conceptual phrase representing the topic of inquiry to data to code and categorize the data, and typically provide the basis for further detailed coding (Saldana, 2009). Second cycle coding methods refer to ways or reorganizing data coded during the first cycle (Saldana, 2009). Pattern coding refers to a way of grouping emergent themes or explanations (Saldana, 2009). These emergent themes, then, were categorized under main themes.

Findings

Findings of the Open-Ended Questionnaire
The descriptive findings of the open-ended questionnaire, presented in table format, are presented below. As mentioned earlier, these findings should be interpreted understanding that these categories represent broad views of participants from their open-ended responses. Because many respondents provided more than one answer to the question, percentages of responses add up to more than 100%.

Close to 86% of the participants felt that autonomy was the single most important factor of self-management (n=77). Concepts of autonomy described by participants included choice, independence, managing one's own health and care, empowerment, and decision-making. Learning coping strategies and skills was also seen as important, with almost 58% of participants indicating this was important. Participants described this as finding resources, dealing with a diagnosis, making informed decisions, planning for the future, and working with partnerships. Formal support was mentioned by only 29% of the respondents, including health care professionals and Alzheimer Societies, while education and information was mentioned by only 27% of respondents. Education included learning to manage, learning about the disease,

necessary resources, and seeking information and assistance. Quality of life was seen to be an important component of criteria by 22% of respondents which included living well, handling day-to-day life, and making adjustments as necessary. Other components of self-management included informal support (17%) such as family, and treatment options (13%) such as managing and improving symptoms and the progression of the disease.

Table 1   What does self-management mean to you?

Definitions of Self-Management	N (N=90)	Percentage (%)
Autonomy	77	85.56
Coping skills and strategies	52	57.78
Formal support	26	28.89
Education	24	26.67
Quality of life	20	22.22
Informal support	15	16.67
Treatment options	12	13.33

Respondents indicated that they felt the two most important ingredients for successful self-management included support (67%) and knowledge (56%). However, other ingredients including coping (31%), control (30%), empowerment (28%) and self-awareness, such as insight into the disease, (26%) were also mentioned by respondents. Setting goals (19%) and acceptance (11%) were also mentioned by respondents.

Table 2   What are the most important ingredients for successful self-management?

Ingredients of Self-Management	N (N=90)	Percentage (%)
Support	61	67.78
Knowledge	50	55.56
Coping skills	28	31.11
Control	27	30.00
Empowerment	25	27.78
Self-awareness	23	25.56
Attitude	20	22.22
Goals	17	18.89
Acceptance	10	11.11

Most participants (80%) felt that self-management in the dementia context was feasible. Only 20% did not feel it was feasible. Upon closer exploration of the individuals who did not think it was feasible, a number of respondents felt that it might be feasible in the early stages of the disease, but not into the later stages.

The comments in response to whether or not self-management of dementia was feasible centred on a number of issues. Many respondents (61%) discussed disease progression as a significant issue that would impact self-management. Support was discussed by 43% of respondents, and the abilities of people with dementia was also mentioned by 38% of

respondents. Choice (19%), coping mechanisms (16%), safety (13%), self-determination (11%), and quality of life (2%) were also mentioned.

Table 3   Feasibility of Self-Management of Dementia

Themed Comments	N (N=89)	Percentage (%)
Disease progression	55	61.11
Support	39	43.33
Abilities	34	37.78
Choice	17	18.89
Coping mechanisms	14	15.56
Safety	12	13.33
Self-determination	10	11.11
Quality of life	2	2.22

Respondents indicated that the most important ingredient for a self-management model of dementia was support (63%) generally, which included both formal and informal support. Assistance with advocacy and other activities was also seen to be an important ingredient by 37% of respondents. Early diagnosis and knowledge of dementia was also stated by 22% of respondents to be important. Access to resources (19%) and informed decisions (17%) were also described as important ingredients in the self-management model of dementia. Finally, 8% of respondents stated that communication was important.

Table 4   Most important ingredients for a self-management model of dementia

Ingredients for Self-Management of Dementia Model	N (N=90)	Percentage (%)
Support in General	57	63.33
Assistance with Activities	33	36.67
Early diagnosis	20	22.22
Knowledge and Information	20	22.22
Access to Resources	17	18.89
Informed Decisions	15	16.67
Communication	7	7.78

Many of the respondents (31%) indicated that they were in the "other" category of professions, many of them being staff at local Alzheimer Societies. By far, nurses (29%) and social workers (21%) made up the majority of professions. Recreation therapists (6%), occupational therapists (4%), nurse practitioners (3%), physicians (2%), physiotherapists (1%) and dieticians (1%) were also represented.

Table 5   Respondents

Professional Group	N (N=90)	Percentage (%)
Other	28	31.11
Nurse	26	28.89
Social worker	19	21.11
Recreation therapist	5	5.56
Occupational therapist	4	4.44
Nurse practitioner	3	3.33
Physician	2	2.22
Physiotherapist	1	1.11
Dietician	1	1.11

Findings of Interviews

The main themes emerging from the data related to philosophies or approaches to self-management, the self-management environment, self-management tasks, and self-management considerations. The philosophies or approaches to self-management, along with the self-management environment were typically discussed by health service providers and partners in care. People living with dementia, however, discussed how self-management was actualized day-to-day, rather than the characteristics of what self-management actually was or the philosophies underlying the concept. The considerations of self-management were discussed by partners in care, health service providers, and less so by people living with dementia. Consistently, however, all participants expressed a desire and a need to self-manage for as long as possible, and to ensure that people living with dementia had the coping strategies to live independently for as long as possible. As one person living with dementia stated:

> *"...Self-management is the true, blunt concept of it. We have to learn to manage ourselves...and what other term can you use? Sometimes in our journey it has to be the truth, and that's maybe a bit blunt for some folks. But it's the truth. To get the best out of life, we have to manage ourselves in the most productive manner...self-management—it's managing yourself to give yourself the best that life can give you..."*

Another health service provider also stated:

> *"...we need a formal self-management program, and to be called that, you know, to make people realize that they can manage it themselves to a certain extent and that [to a] certain extent they should be taking that piece of it that's theirs and be a partner in their care and do what they can, but still maintain a happy, healthy lifestyle."*

Philosophies and Approaches to Self-Management

There were four key themes relating to the philosophies and approaches to self-management, including ***empowerment, control, "managing", and partnerships and "co-management"***. As mentioned previously, many of these ideas were discussed by health service providers, although partners in care did mention some of these issues as well.

Many participants felt that a self-management approach in dementia would greatly enhance the empowerment of people with dementia and their partners in care. As one health service provider stated, *"I think that it would be a golden opportunity for people with early stage dementia to be able to feel empowered and feel confident at probably the worst time in their life after they've been diagnosed, and know there's hope out there." (Health service provider)*

Another important philosophy of self-management was related to control. While some of this control was related to control over formal support services, much of the control was also related to people living with dementia and their families having control over the impacts of the disease and its progression, rather than reacting to the changes that the disease caused in people's lives. As a health service provider commented, *"And I think to retain dignity and control. Of course, everybody has different stages that they go through. But they're very aware of the changes."* As another health service provider stated:

I think a better self-management model – that would be the understood piece that you determine what you need. You determine how you want your life to look. You determine the things that define quality of life for you and we'll support that happening. So I think it's a very different entry point.

The third key approach to self-management was about "managing". This theme included managing one's self, one's care, and one's health. One health service provider suggested that self-management was about *"...enabling people to take on more of an active role and managing their own care needs; and being able to predict what the care needs might be."* Another health service provider, who was also a former partner in care, stated that self-management was about

"...empowering the patient...the person with the disease and the care team around them to get what they need when they need it, hopefully with a minimum of gaps in service progression and with some ongoing support to negotiate the system so that there's some consistency throughout it.

Finally, the fourth key approach to self-management with dementia was about partnerships. Most importantly, people identified the importance of families and partners in care, and stated that self-management should be seen as "co-management": *"it really was more of a co-management rather than a self-management. I mean, you can't leave a dementia patient to self-manage entirely." [Health Service Provider].* As another health service provider stated:

And I saw how easy it is to work, how respectful it is. How it creates that partnership rather than sort of the professional is up here and the client is down here. It levels the playing field a bit and I think it adds dignity to the person at a time when they really, really need that. So from that perspective, I really like the model as you probably already have figured out. And it works. I mean, you know? If people go after the things they want and they're supported to do it and supported to overcome their barriers, most people can achieve some success. [Health Service Provider]

The Self-Management Environment

There were many themes that emerged that solidified the importance of taking a social ecological approach to self-management. The **self-management environment** refers to a number of characteristics, including **the importance of family and spousal or partner support, peer support often found through support groups, informal support through friends and community**, and **system support**.

The importance of family was stressed by people living with dementia, partners in care, and health service providers. As a person with dementia stated, *"I think if somebody else is there for breakfast, you're more likely to get up and get it for both of you."* The importance of family was also stressed by a spouse:

And another thing that's important is how much does your family understand. We had our two kids here a couple weeks ago and just sat down and talked with them about where we're at and also what we see for the future; and that don't be talking nursing

home because that's not what we want if we can avoid it. We want to do what we can at home. … Try to get the family support and maybe you even need somebody as a …you know, to help with the family understanding.

The importance of peer support was stressed by people living with dementia and their partners in care. Not only did people living with dementia describe how they benefitted from the support of others diagnosed with dementia, but they were also able to contribute to the well-being of others. Another person living with dementia stated, *"[t]he camaraderie that we've formed between us here, we're just one big happy family. It's been fun and it's helped through a lot of rough spots."* Another person living with dementia stated, *"However we could lighten the burden for somebody. But the only time that's happened is when we've been at Alzheimer's meetings; and then it's mutual – very mutual."* As another person living with dementia stated,

That's one of the things I would encourage someone, even if they don't consider themselves joiners. And I did not. The whole group idea kind of made me a little bit nuts… and you have to remember that this is a club that nobody wants to join. But once you're in it, it has benefits that you just can't even begin to imagine.

Informal support found in friends and the communities in which people lived was also described as important. One participant living with dementia stated the benefits of living in a small town: *"And I think that's just as important as any luxury you could go to, any groups or anything. If you've got the community with you and watching out for you, that's a great gift in itself, which they don't have in large urban areas."* A spouse described how supportive her neighbours were:

Actually, we've been blessed with a lot of people that do understand. Like we have a neighbour here that used to work for the CCAC. And, like our neighbours next door around here, they just know that [my husband] can't do some of the things he used to do, and it's largely the arthritis. It's more the arthritis. But they pitch in and help us. And, you know, people just – for the most part, they seem to understand.

Her husband then stated, *"When people see you come in with a cane and before you get to the door, they open the door. People are good, you know. This is a good community to live in. They're so kind."*

System support was also described as essential to successful self-management. The first important piece was ensuring that people got the appropriate and accurate information upon diagnosis. However, once diagnosis had occurred and the person was in need of system supports, the importance of an integrated system was clearly stated. In order for self-management to be successful, one health service provider stated,

I think in that [support] group it was good and I think that's what the emphasis of that Alzheimer's group is, to try to get people, the caregivers especially, to be able to manage these people at home so that the system isn't flooded out with it. I think it's really…it's a good idea. But I think you have to be able to tie some type of actual supports in place with it. I've been in the system a really long time, but there aren't that many of these clients that get any mental health help because there aren't the resources out there. And

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> *I think you can't just do it with a self-management program. You have to have some kind of supports that you can lessen the burden on the people.*

Another health service provider stated,

> *I've seen the Chronic Disease Self-Management course. Like I said, I've facilitated that and you could get this excellent buy-in from a client and they're really motivated to go home and start managing their own care and recording their medications and doing all this kind of stuff. And then they get to their physician's office or into the healthcare system and they're managed and they become back to being dependent because the system's not ready to change. The system hasn't changed and likewise you have students who might come from a very proactive type of a program where they talk about goal-setting and they talk about all those kinds of things. And then they're all set to do that and they come into that healthcare system or they come into a system where it hasn't changed yet, you know. And it kind of needs to happen at the same time. It needs to be a philosophy that is supported, because if you have a couple individuals doing that and they go out and they try to do that and the system doesn't support it, you know, the pharmacist and the pharmacy doesn't; or the physician doesn't do that, then, you know, it's just going to fail. So it's kind of having that buy-in from people as well.*

The importance of a system that was integrated and sustainable was one of the important components to successful self-management across the continuum of dementia care.

<u>Self-Management Tasks</u>

People living with dementia described many tasks that they performed every day to successfully self-manage. Most of the individuals that participated in the individual or group interviews were successfully self-managing. Many were in the early stages of the disease process, although some were a little farther along and less independent than others. They all, however, described day-to-day activities that helped them to self-manage. These tasks are divided into the same self-management tasks described elsewhere (Strauss & Corbin, 1988) including: **disease management, role management**, and **emotional management**.

People living with dementia described how they managed the disease and their physical and cognitive well-being, including physical activity, medication management, routines, and cognitive management. Participants described a variety of physical activities including hockey, golf, biking, hiking, skiing, running, fitness courses, swimming, and walking. As one person living with dementia who was in his mid 80s described, "*That's one thing that I really miss, is the 10-mile road race. The last one was about five years ago, was the year that I entered the 10-mile road race. I just can't. Five k seems to be my limit now, and that's it. So I'm satisfied with that and I'm doing that three or four times a week, and that's a good amount.*" Many others described the importance of physical activity. Various strategies were also used to manage medication and ensure that medications were taken every day, including leaving vitamins and the pill bottle on the table until medications were consumed. Routine was also described as very important in self-managing day-to-day. *"Routine is one of the best things, I think, to keep us going...you don't have to try and keep it in your mind all the time..." (Person living with dementia)*. Finally, various cognitive exercises and strategies were used, including sticky notes,

calendars, blackberry, and relying on family. Other cognitive exercises included playing card games, computer games, and attending memory programs at the local Alzheimer Society.

Role management encompassed the importance of social support as mentioned above, including family support, friend support, and peer support. Individuals living with dementia also talked about the importance of being open about their diagnoses. As one person living with dementia stated, "*Don't feel that it is some sort of exotic disease you've got to hide about. Be open. Be up front. Do the things you like to do. Some things might have to be modified, but keep on going as long as you can.*" As another person living with dementia stated, "*And I've accomplished a lot in that 10 years that I otherwise wouldn't have experienced. Like I advocated for memory loss. I've written poems, which I never did in my life. I was a keynote speaker. I just advocated through the newspaper, friends and whatever.*"

Emotional management, then, described a number of emotional tasks that people living with dementia had to accomplish in order to accept the diagnosis and continue living a well life. First, grief and acceptance of a diagnosis of dementia was integral to being able to successfully self-manage. A person living with dementia stated,

> *I think you have to allow yourself time to accept and really realize what's going on and what's going to go on. I know for myself I was probably in a little bubble of denial for awhile as down the road, you know. And it takes a little while to kind of process and I think people need to, from my experience, we need to just allow ourselves that and not jump ahead; and just be where we are for awhile and accept that.*

The need for a positive attitude was also evident. The following statements are evident that people living with dementia felt that a positive attitude was critical to living well.

> "*Hang in there. As one of my peers said, at least I'm still on the right side of the grass.*"
> "*Live for today.*"
> "*And just cope with it the best you can and try to be cheerful...*"
> "*...just take one day at a time. That's all you can do.*"

Self-Management Considerations

While most participants felt that people living with dementia could self-manage, there were a number of factors to take into consideration when developing self-management strategies and interventions. First, participants felt that **cognition and awareness** were very important considerations in self-management strategies for people with dementia. One health service provider stated, "*So we need to kind of taper that model so that it meets the people where they're at; and it needs to be simplified in that way, I think.*" The progression of the disease was mentioned by a number of health service providers and family members: "*...progression of dementia or any disease will cause challenges with compliance or adherence to medication use or inability to have proper judgment over certain choices about their health, whether it be taking medications or even just going to appointments*" (health service provider). The unpredictability of the progression of the disease was also seen as an important consideration. As one health service provider stated,

I think any kind of self-management plan for dementia has to change over time and that makes it more complex and probably difficult to create and manage. The difference with any other self-management plan, for example, diabetes or hypertension or other chronic disease is that it may get worse over time, but the person's role in the care may not change so much. Whereas the dementia, as it progresses, their role will change and I think it needs to reflect that. And I think really being able to communicate the benefits to both the person who has received the diagnosis and the broader public of empowering people to manage their own care and the sense of self-worth that can come from that might get buy-in.

Another consideration was the possibility of people being in **denial of a diagnosis**. One health service provider stated, *"You know, they might not want to admit to themselves or to the group that they have dementia, especially in the early stages where they're still dealing with it."* As another health service provider stated, "*I think [dementia is] probably one of the biggest chronic diseases that people are in denial about and it's also probably one of the most missed.*"

Other general considerations included **the impact of dementia on caregivers** and the capacity of caregivers, or partners in care to support people with dementia in self-management. **Co-morbidities and the complexities of conditions** were also considered to have an impact on self-management. The importance of an **early and accurate diagnosis of dementia** was also considered necessary in order for self-management to be successful. And finally, **the ability of the system to support self-management** was a very significant consideration, and one that most participants viewed as the catalyst to making self-management a success or failure for individuals.

In summary, the respondents to both the questionnaire and the participants in the interviews felt rather strongly that self-management was entirely possible in the context of dementia, and that people living with dementia, particularly in the early stages, had the capacity to self-manage. Even more strongly, however, was the conviction of people living with dementia and some partners in care and health service providers that self-management was a right and was something that would greatly enhance quality of life and well-being, whether it was learning coping strategies and developing peer support, or relying on system supports but having control over those supports. However, the supports, including family, friends, community, and system support, were vital to ensuring the success of self-management for people living with dementia. While all participants agreed that self-management was an important goal to work towards in dementia care, flexibility and sensitivity will be required as interventions and strategies develop in the future. However, self-management is possible for people living with dementia. As a person living with dementia stated,

So for anybody that's newly diagnosed – yes, go through your five steps of grieving and then take the bull by the horns and just really, really, really think about something different and new to try to do. And it's amazing what an individual can do when you really put your mind to it.

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