Community-dwelling older adults with memory loss

Needs assessment

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Abstract

Objective To identify the health-related needs of community-dwelling older adults with mild memory loss.

Design Qualitative study using semistructured, audiotaped, face-to-face interviews and focus groups.

Setting A large community in Newfoundland.

Participants Twenty-two adults between the ages of 58 and 80 years.

Methods This needs assessment used a qualitative methodology of collecting and analyzing narrative data to develop an understanding of the issues, resources, and constraints of community-dwelling older adults with mild memory loss. Data were collected through semistructured, audiotaped, face-to-face interviews and focus groups. Transcripts of the interviews were analyzed using interpretive phenomenologic analysis.

Main findings Three constitutive patterns with relational themes and subthemes were identified: forgetting and remembering, normalizing yet questioning, and having limited knowledge of resources. Participants described many examples of how their daily lives were affected by forgetfulness. They had very little knowledge of resources that provided information or support. Most of the participants believed they could not discuss their memory problems with their family doctors.

Conclusion It is important for older adults with mild memory loss to have access to resources that will assist them in understanding their condition and make them feel supported.

EDITOR'S KEY POINTS

- Many older adults endure the effects of impaired memory caused by early cognitive decline without seeking medical attention because they are unaware that they are having problems with memory or because the possibility of receiving a medical diagnosis of progressive dementia such as Alzheimer disease frightens them.

- Older adults were reluctant to discuss their declining memory with their family doctors for reasons such as believing that their family doctors were not well enough informed on the subject of memory impairment, thinking that doctors would view their memory problems as not serious, and feeling embarrassed.

- Older adults with memory problems need to have more information about what they are experiencing and need to know where to go for answers. They need family doctors who are knowledgeable and confident in their ability to discuss the problem of memory loss, answer questions, and diagnose and assist in managing the illness in a supportive environment.

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Adultes vieillissants qui vivent dans le milieu naturel et présentent des troubles de mémoire

Évaluation des besoins

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Résumé

Objectif Identifier les services de santé nécessaires aux adultes vieillissants qui vivent dans le milieu naturel et présentent de légers problèmes de mémoire.

Type d'étude Étude qualitative à l'aide de groupes de discussion et d'entrevues individuelles semi-structurées enregistrées sur ruban magnétique.

Contexte Une importante communauté de Terre-Neuve.

Participants Vingt-deux adultes de 58 à 80 ans.

Méthodes Pour évaluer les services requis, on a utilisé une méthode qualitative de collecte et d'analyse de données narratives afin d'identifier les problèmes, ressources et contraintes propres aux adultes vieillissants qui vivent dans le milieu naturel et présentent de légers troubles de mémoire. Les données ont été recueillies à l'aide d'entrevues individuelles semi-structurées enregistrées sur ruban magnétique et de groupes de discussion. L'analyse des transcrits des entrevues a été effectuée par analyse phénoménologique interprétative.

Principales observations On a identifié 3 modèles constitutifs avec des thèmes et sous-thèmes relationnels: oublier et se rappeler, normaliser mais aussi se questionner et mal connaître les ressources. Les participants ont cité plusieurs exemples de la façon dont les oublis affectent la vie de tous les jours. Ils avaient une connaissance très limitée des ressources pouvant les renseigner ou les aider. La plupart croyaient qu'ils ne pouvaient pas aborder leurs problèmes de mémoire avec leur médecin de famille.

Conclusion Il est important que les adultes vieillissants qui souffrent de légers troubles de mémoire aient accès à des ressources pouvant les aider à comprendre leur condition et à se sentir appuyés.

POINTS DE REPÈRE DU RÉDACTEUR

- Plusieurs adultes vieillissants souffrent des effets d'une mémoire déficiente résultant d'une baisse précoce des fonctions cognitives sans pour autant consulter un médecin, soit parce qu'ils ils ne sont pas conscients d'avoir un problème de mémoire ou parce qu'ils craignent qu'on leur dise qu'ils ont une démence progressive comme la maladie d'Alzheimer.

- Les adultes vieillissants hésitaient à aborder leur problème de mémoire avec leur médecin de famille, entre autres parce qu'ils croyaient que celui-ci ne connaissait pas suffisamment ce sujet, qu'il ne prendrait pas au sérieux leur problème de mémoire ou parce qu'ils ne se sentaient pas à l'aise d'en parler.

- Il est important de mieux informer les adultes vieillissants qui présentent des troubles de mémoire sur la nature de leur problème et sur les ressources qui peuvent les renseigner. Ils doivent en parler à des médecins de famille qui connaissent le sujet et qui se sentent compétents pour discuter des problèmes de perte de mémoire, répondre aux questions, poser un diagnostic et participer au traitement de cette condition avec l'appui du milieu.

Cet article a fait l'objet d'une révision par des pairs.
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A substantial number of older adults with some form of early cognitive decline that results in memory impairment are living independently in communities.[1] Although there are a number of classification systems, cognitive decline generally falls along a continuum from age-associated memory impairment to mild cognitive impairment (MCI) to dementia.[2] Age-associated memory impairment is considered the mildest form of memory impairment, characterized by the absence of relevant changes in instrumental activities of daily living and very little impairment in short-term memory; language is not affected and visual-spatial abilities are slightly affected.[3] Mild cognitive impairment is also a relatively benign form of memory impairment in the presence of otherwise normal functioning. Mild cognitive impairment presents a more severe form of memory loss than age-associated memory impairment, and, although there is no dementia, there are reports of mild difficulties in complex daily living activities.[4] Individuals with MCI have a moderate risk of developing dementia.[3] Reported negative health-related ramifications of early cognitive decline include, but are not limited to, household accidents, medication errors, motor vehicle accidents, elder abuse,[5] somatic complaints, anxiety, loss of self-confidence, feelings of irritation and anger toward others, and loss of relationships with family members.[6] Mild cognitive impairment has been reported to be distressing for spouses of those with early cognitive decline, and marital quality diminishes as a result of bothersome behaviour.[7]

Many older adults endure the effects of impaired memory caused by early cognitive decline without seeking medical attention.[1] There are a number of reasons why older adults with early cognitive impairment might not seek medical attention, but literature in this area is limited. First, some older adults might simply not be aware that they are having problems with memory.[1] Second, the possibility of receiving a medical diagnosis of progressive dementia such as Alzheimer disease might frighten older adults and lead them to avoid seeking a diagnosis.

Although older adults might not seek medical attention, many of them are able to recognize that they have some impairments of memory[8,9] and that they have health-related needs. As a result they are often in a position to determine what resources would be beneficial to meet their needs. Although research in the area of understanding the experiences of those affected by early cognitive decline and memory loss is increasing,[10-13] there is limited literature addressing the self-identified needs of older adults with age-associated memory impairment or MCI. Therefore, the primary objective of this study was to identify the priority health-related needs of community-dwelling older adults with mild memory loss.

METHODS

Design

This needs assessment used an interpretive qualitative methodology of collecting and analyzing narrative data from community-dwelling older adults within a large community in Newfoundland. In this study, the goal was to understand the experience of memory loss in the lives of individuals with MCI. By listening to the voices of the people in this study and attending to them as they experienced memory loss, the meaning of this experience and the issues around seeking and finding health services for their memory problems were uncovered.

Participants

Ethical approval to conduct this study was obtained from the appropriate local research ethics committee. To be included in the study, individuals had to be older and living independently in the community. They had to acknowledge that they had some impairment of memory, and could not have been diagnosed with dementia such as Alzheimer disease. Participants were a purposive sample of 7 men and 15 women between the ages of 58 and 80 years living in their own homes in the community. Participants represented a range of social and educational backgrounds. All participants except 1 were retired, and all except 1 were white and of European origin. Although the interviews suggested that the participants appeared to range somewhat in the severity of their cognitive function, participants were not excluded unless they were unable to communicate well enough to answer the research questions. None of the participants had problems understanding or answering any of the interview questions. Furthermore, even if participants appeared to be in the early stages of dementia but were still living and functioning independently at home, their experiences were considered relevant to the research question.

Data collection

Data were collected through semistructured, audiotaped, face-to-face interviews and focus groups. A list of semistructured interview questions was used to help guide the interviews (**Box 1**). After individual interviews were completed, all the participants were invited to attend a focus group. Eleven participants agreed to attend a focus group and a total of 3 focus groups were conducted. Eleven participants did not attend a focus group. Reasons for not attending included the following: not being able to be reached by telephone (2), illness (2), they believed that they had nothing more to offer in terms of discussion (3), they were uncomfortable discussing their problems in a group setting (2), or there was no reason given (2).

The primary researcher (K.P.) facilitated the focus group interviews. Although focus group questions were similar to the initial interview questions, the focus groups stimulated a spontaneous exchange of information and ideas, and were a means of offering the participants an opportunity to meet and share information with others who had similar experiences. Thus, the focus groups enabled the researchers an opportunity to attain additional information that did not surface in the initial interviews with the participants. Credibility was also strengthened, as focus groups have high face validity. The focus groups allowed for confirmation of the researchers' analysis of the initial interview data. Credibility is strengthened when true-life descriptions or interpretations of experiences are recognized by the people who had the experiences or by others who identify with the experiences.[14]

Data analysis

Transcripts of the interviews were analyzed using interpretive phenomenologic analysis. Data analysis proceeded according to the 7-step method of textual analysis as described by Diekelmann et al.[15] The first step in the analysis involved reading each text in its entirety to grasp the uniqueness of the descriptions of the phenomenon. Themes were then identified using the selective or highlighting approach, whereby text from each interview was read several times and statements that appeared revealing about the phenomenon were underlined or highlighted.[16] The primary researcher (K.P.) took the lead in identifying the themes. This was followed by consultation with other members of the research team. The other members either supported the analysis or offered constructive criticism. The third step consisted of an interpretation of each interview. Next, the relational themes (new layers of explanation for the thematic aspect of the experiences that are similar across the participants' stories) were identified. Finally, a search for constitutive patterns occurred. This involved reading the text from all the interviews in order to obtain a global perception of the stories, and depicting the relationship between the relational themes that existed in all the interviews and focus groups. As per step 6, other relevant sources of literature were used to enhance the interpretation and to determine whether the interpretation made sense in light of what was already known, or was so outrageous that it warranted further investigation. Finally, the relational themes and constitutive patterns were again discussed and evaluated in terms of thoroughness and agreement among the other members of the research team to enhance credibility of the analysis. The process of data analysis, while following the steps identified by Diekelmann and colleagues,[15] was not linear but rather circular in nature, with a continuous process of relating the part of the text to the whole of the text.

Box 1. Interview questions that were used to help guide the interviews

1. Tell me about your memory problems.

2. How do they affect your day-to-day living?

3. What are the main concerns regarding your memory problems at this time?

4. What, if any, resources do you use to assist you in day-to-day living with your memory problems?

5. Are you aware of any available community resources that would assist you in your day-to-day functioning? Do you avail yourself of these resources? If not, why?

6. What do you think would be helpful to assist you with living with your memory problems?

FINDINGS

Our analysis of the data identified 3 constitutive patterns consisting of relational themes. The constitutive patterns are forgetting and remembering, normalizing yet questioning, and having limited knowledge of resources.

Forgetting and remembering

During the interviews, participants were first encouraged to talk about their memory problems. The stories they told were mainly of how they were now becoming forgetful, as well as how they were later able to remember what had been forgotten.

Forgetting and remembering little things. Participants told many stories about forgetting and remembering little things—stories about misplacing things such as car keys. Although not considered a "big deal," the participants found this to be quite frustrating and sometimes a little scary.

Participants also frequently talked about forgetting to do little things. Participants gave examples such as putting the cat out but forgetting to let her back inside the house, or going into a room and forgetting why they went in there. For several participants, remembering to do these little things often occurred spontaneously without any prompting, while other participants found that they were now consciously trying harder to remember. For some participants, keeping routines helped them to remember.

> I recognize it all now; these little things are not a problem. But I tend to more than I ever did before put certain things in certain places. I keep putting them in the same place and sticking to routines.

Forgetting and remembering important things. Participants told several stories about forgetting important things. Examples included forgetting to go to important appointments, forgetting to take medications, forgetting that something was cooking on the stove, and forgetting names and telephone numbers. To help them remember important things, participants would often write notes as reminders to themselves. These notes were usually kept in places easily visible or accessible (eg, the refrigerator). Participants also stated that when they had forgotten a name, it was best not to try too hard to remember; they found it was easier to remember the name by just relaxing and letting the name come to mind on its own time.

Not only did participants discuss forgetting to do important things, but they also told stories of "forgetting how to do important things." Participants told stories about forgetting how to count money or how to cook a long-known favourite recipe. Participants stated that it was easier to remember by taking things slowly and concentrating much harder.

Forgetting and remembering when reading. Several participants discussed how they could no longer recognize certain words while reading, which caused them to have to read very slowly. Although they might remember the words eventually, they often found it was no longer worth the effort.

> It could be the simplest foolish little word, but all of a sudden I'm hung up and it might take me a while to figure it out what the word is. As a rule I can read, but now I'm very, very, slow. I used to be very fast. Like if you put something up on the screen, I know the words, but I can't read it before they change it.

In another twist of this theme, 2 participants described not being able to remember the meaning of the words they read, even though they were simple, familiar words. Also, 2 participants discussed not being able to recall what they were previously reading. They eventually remembered after rereading what they had previously read. "If I put the book down for 2 or 3 days, I've got to go over 3 or 4 pages to pick up on where I left off, to jog my memory, you know, who was who there now."

Forgetting and remembering during conversation. Forgetting during conversation was also problematic for several participants in the study. One woman reported being frustrated: "When [you're] talking and all of sudden you stop and you can't remember what you're talking about." For this woman, concentrating harder did not help but rather made remembering more difficult. For another woman, part of the conversation was sometimes completely forgotten shortly after it had occurred. For 2 other participants, the problem presented itself as unknowingly repeating the conversation.

Forgetting and remembering when driving. The relational theme "forgetting when driving" was presented in 2 distinct ways by participants. For 3 of the participants, the problem was forgetting how to get where they were going. For one man, even having the directions written down did not help.

> You know, sometimes when I'm driving and I'm going someplace I forget, I have a general idea of where I'm going if I've been there before but [am] not quite sure of the actual familiarity with the streets. I take a wrong street and say, "I shouldn't have done that." Directions, even reading a map; you know, if somebody tells me to take 2 lefts or right, gives me a long list of directions, I'm likely to end up way up here somewhere. I don't have a good memory for that kind of thing.

Despite getting lost, this man would eventually be able to figure out how to get to where he was going. "But I can usually backtrack and find it. I've never been like completely lost and couldn't find my way."

For other participants, forgetting while driving was revealed during stories about not remembering where they were going. One man explained the following:

> And then I drove out. I came out of the driveway and I passed [name of street]. I kept going. I passed [location] and I said to myself, "Now, where am I going?" And I'm still driving down. I passed the park. I had to stop for the ducks; they were trying to cross the bridge. It's a real beautiful sight actually and I said, "Oh my God, where am I going?" It took me a while to remember where I was going. I had to rethink about my morning plans before it came to me.

Helping their memory. All of the participants believed that they were purposely doing things that helped them remember. They had discovered, over time, that by doing certain activities the ability to remember was much improved. Examples included reading, doing crossword puzzles, socializing, staying active, and eating healthy. Socialization with others was deemed by the participants to be very important for promoting a healthy memory. One woman stated, "But anyone who

keeps themselves physically and mentally challenged or is fortunate enough to have interaction with at least one other person have [*sic*] much better memories."

Normalizing yet questioning

Despite having identified that they were having memory problems, the participants would often normalize the forgetfulness. This became evident in 2 ways: viewing the problem as normal for their age, and viewing the problem as nothing big. Although participants often normalized the problem, they still called into question the seriousness of what was happening to them.

> I'm not all that worried about it. If there was a worry, it would be that it's getting worse and I think of this Alzheimer's [disease]. But I'm not dispelling or ignoring that it might happen but maybe it is a bit of a concern; but it's just that my memory is a bit bad, and it's also the fact that my brother has got it really bad.

Having limited knowledge of resources

Participants were asked if and where they would go for information, whom they would feel comfortable talking to, and what resources they would like to see available within their community. Overall, participants had very limited knowledge of resources that could assist them in dealing with their forgetfulness.

I don't know. Most of the participants had limited knowledge of where to go to find out more about their memory problems. The only resource that participants thought might be available within their community was the local Senior's Resource Centre. The Senior's Resource Centre in the city that this study takes place is a prominent organization catering to the needs of older adults.

Only 1 participant discussed the Alzheimer Society as a possible source of information. However, this man thought that the Alzheimer Society was probably already overworked and was not the best option because he did not have Alzheimer disease.

Wanting someone to talk to. Several participants reported just wanting someone to talk to and share information with. They stated that they wanted to speak with someone who knew something about what they were experiencing. A female participant said, "Well, it wouldn't hurt to have self-help groups like they do with other illnesses." Several participants stated that they did not want to bother or worry their children, and that they really did not know whom it was best to talk to about their forgetfulness. Because focus groups gave participants the opportunity to talk about and share their thoughts regarding their memory problems, all participants who attended reported that the focus groups were very beneficial.

Not my family doctor. Several participants stated that they did not feel comfortable discussing forgetfulness with their family doctors because their doctors were not really "up" on the problem of memory loss for those getting older. One participant stated, "So, who do you go to? And it seems like the family doctors aren't into it. I don't know where to go to get answers."

Another participant said, "They know how to take care of babies, but do they know how to take care of seniors?"

One female participant reported that she thought her memory problem was too unimportant to bother her family doctor about it.

> But I mean GPs just don't go around and order [a] test for anyone walking in with some kind of forgetful tale. I mean, you wouldn't have enough machines in the province to scan us all.

Another participant believed that consulting a health care professional for her memory problem would be embarrassing. She also believed that her memory problem might be viewed by others as too unimportant.

> I never thought of going and seeking something out, and I think, too, it's because I probably felt embarrassed a little bit, and you say, "Oh my, you're going to see a nurse, a doctor, or a psychologist or whatever. You can't remember things? Sure, lots of people can't remember things."

Only one participant stated that she would see her family doctor for her memory problem. This woman seemed to have developed a good rapport with her doctor; however, she had not seen him at the time of the interview.

DISCUSSION

Although it is not the aim of qualitative research to make generalizations to the entire population, the findings of this study do add to the understanding of self-identified needs of older adults with memory problems as they present in one community.

It is interesting to note that the participants in this study did not report any serious negative health-related ramifications of early cognitive decline such as medication errors, motor vehicle accidents, abuse, anger toward others, and loss of relationships with family members as was previously found in the literature. Although it is impossible to know for sure why it was not a problem for the participants, it might be because most participants identified themselves as being in the very early stages of cognitive impairment, with

mild forgetfulness being the essence of the problem. Several participants did discuss forgetting while driving, which, if questioned further, might have revealed more serious consequences; unfortunately, participants were not specifically asked about more serious driving experiences during the interviews.

When participants were asked about what they thought would be helpful in assisting them with their memory problems, they described a need to have more information and to know where it was best to go for answers. Most of the participants were eager and enthusiastic to meet and share their concerns and information with the primary researcher (K.P.), and at least half of them were willing to share their stories with others with mild memory loss. This is likely owing to the beneficial nature of group support. A 2008 study[17] showed that patients with MCI found support groups to be stimulating, supportive of self-esteem, and helpful in finding new ways of coping with everyday life and social relations.

Despite their questioning of what was happening to them, as well as having limited knowledge of where to go for answers, participants were reluctant to discuss their declining memory with their family doctors. Participants' reasons included fear of a diagnosis of Alzheimer disease, believing their family doctors were not well enough informed on the subject of memory impairment, believing their family doctors would view their memory problems as not serious, and feeling embarrassed. Although we can only surmise why participants had such beliefs, it is likely that prevailing pervasive stereotypes of aging might be a factor. Indeed, several of the participants stated that they believed their failing memory was a normal part of getting older. Despite the fact that the gerontological and geriatric specialist communities are advocating that age itself is not a disease, a large percentage of older adults still attribute poor health conditions and disability to aging, and thus are less likely to seek health care for what they believe are age-related conditions.[18,19] However, many of these age-related conditions are treatable, and unfortunately older adults are missing out on timely interventions. A second possible factor for participants' reluctance to seek medical attention for early memory loss might be family physicians' attitudes toward and beliefs about mild memory problems in older adults. A qualitative study of general practitioners' experiences in diagnosing early dementia found that family doctors were sometimes reluctant to pursue a diagnosis in patients with possible early dementia if the patients were in otherwise good health, even if they suspected that there might be a problem. In addition, the study found that family doctors acknowledged that a diagnosis of dementia was one that "no one likes to get"; thus, they avoided disclosing it to their patients.[20] Also, family doctors indicated that they were sometimes reluctant to treat patients with what they viewed as "normal" problems related to the aging process.[20,21] Physicians must be clear in their understanding of the debate between normal aging and the disease process. Although the lines between age-associated memory impairment, MCI, and dementia are blurry, the problematic nature of dementia as a condition should not undermine family doctors in the care of their patients.

What was clearly an important need for the participants in this study was family doctors who were knowledgeable and confident in their ability to discuss the problem of memory loss, answer questions, and diagnose and assist in managing the illness in a supportive environment. Pimlott et al[22] found that family physicians' compliance with the use of the 1999 Canadian Consensus Conference on Dementia clinical practice guidelines varied from fair to good owing to their lack of awareness of the guidelines or their feelings of industry bias from pharmaceutical companies. Further to this, in an effort to understand the challenges Canadian family physicians face in providing dementia care, Pimlott et al[23] conducted focus groups with family physicians and found that family physicians expressed substantial uncertainty about diagnosing dementia mainly because dementia was seen as more complicated and difficult than other chronic conditions; physicians also had uncertainty about the management of dementia once a diagnosis was made. They concluded that family physicians' views should be included in the development and dissemination of future dementia guidelines.

Limitations

The main limitation of this study is that the data are based on interviews of a small number of individuals from just one community. Thus, it is difficult to generalize to the population. In addition, the project was qualitative and exploratory in nature and therefore the conclusions are somewhat broad. Nonetheless, the information gathered can guide future work in helping to focus attention on both the types of concerns held by older adults, as well as their lack of knowledge of where to go for help. Finally, the study highlights the social stigma of age-related memory loss and could be used to argue for a public service campaign to increase awareness of the problem, as well as to identify the resources available to help seniors with mild memory difficulties.

Conclusion

Psychosocial intervention research for individuals with age-associated memory impairment or MCI is sparse. Results show that individuals with MCI have little knowledge of resources available to them and are reluctant to approach their family physicians for assistance. It is highly probable that an individual with

memory loss will not receive much help or support until a diagnostic assessment is sought. Until there is heightened awareness of age-associated memory impairment or MCI among primary caregivers such as family physicians, an early diagnosis and supportive care will not be readily available.

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Contributors
Dr Parsons was the primary investigator of this study and had a considerable role in data collection and data analysis. **Dr Parsons** also took the lead in writing the manuscript, with input from the other members of the research team. **Dr Surprenant, Ms Tracey,** and **Dr Godwin** assisted with data analysis and manuscript writing.

Competing interests
None declared

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