# **Rural and Remote Health**

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# ORIGINAL RESEARCH

# Maintaining health and wellness in the face of dementia: an exploratory analysis of individuals attending a rural and remote memory clinic

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### ABSTRACT

**Introduction:** Worldwide, countries are calling for a chronic disease management approach to people with dementia. In response, 'living well' with dementia and 'supported self-care' frameworks are being adopted by advocacy and volunteer organizations, and more attention is being directed towards health and wellness promotion as a critical component for 'living well'. This exploratory study examined the health and wellness self-management behaviors of patients attending a rural and remote memory clinic; and relationships between engaging in health and wellness behaviors and psychological and neuropsychological function, independence in daily activities, and balance.

**Methods:** The cross-sectional sample comprised 260 patients referred to the Rural and Remote Memory Clinic (RRMC), Saskatchewan, Canada. Patients were diagnosed with amnestic or non-amnestic mild cognitive impairment, Alzheimer's disease (AD), or non-AD dementia. Via questionnaire, patients were asked how many days a week they exercised for at least 20 minutes, if their diet met the *Canada's Food Guide to Healthy Eating* recommendations, and what they did to maintain their psychological health. Patients completed a depression scale, a neuropsychological battery, and a balance scale. Caregivers completed the Functional Assessment Questionnaire. Questionnaire data were analyzed using descriptive statistics and correlational analyses. Bivariate associations between variables were assessed using point-biserial and Spearman's correlations, where appropriate. Open-ended responses were analyzed thematically.

**Results:** Participants were aged between 44 and 97 years, and had between 0 and 20 years of formal education. About half of those with Alzhemier's disease and more than half of the other diagnostic groups reported having five or more chronic conditions. Over a

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third of the total sample reported not exercising at all on a weekly basis. Less than half (42.7%) of the Alzhemier's disease group reported exercising for 20 minutes less than three times per week, while more than half of the other groups reported exercising for 20 minutes less than three times per week. Associations between exercise and tests of neuropsychological function and balance were statistically non-significant for the non-AD dementia group. In contrast, for the group with AD, engagement in exercise for 20 minutes for three or more times a week was moderately associated with better Stroop interference test scores and better balance. Seventy-four percent reported they met most or all of the *Canada's Food Guide to Healthy Eating* dietary recommendations, and 71% indicated they were engaged in activities to maintain their psychological health. Although many who reported engaging in activities to maintain their psychological health reported more than one activity, only 2.1% reported engaging in a combination of physical activities, social activities, and mentally stimulating activities.

**Conclusions:** Patients referred to the RRMC reported good nutrition habits and participating in a variety of activities to maintain psychological health. Engaging in exercise and good nutrition was found to have beneficial effects for the sub-sample of patients with AD. Patients and their caregivers may require additional education and information regarding beneficial health and wellness promoting behaviors related to their diagnosis and concurrent comorbid conditions.

Key words: cross-sectional studies, dementia, exercise, health, health promotion, nutritional status, patient, self care.

### Introduction

More than 35 million people worldwide are living with dementia<sup>1</sup>. This number is projected to increase to 100 million by 2050, with a corresponding estimated global dementia-related cost of \$US604 billion (2010 projection)<sup>1</sup>. Clearly, the prevalence of dementia will have significant health, social, and economic impacts in the 21st century. Of particular concern are the considerable socioeconomic consequences of dementia caused by the extent and duration of dementia-related disability, cost of care, and loss of productivity of those living with dementia and their caregivers<sup>1</sup>. Dementia is now viewed as a chronic disease, similar to diabetes, HIV, and multiple sclerosis. It is a protracted condition that can be controlled, but cannot be cured. As a result, countries across the globe are calling for a population health and a chronic disease management strategy approach to dementia, comprising early intervention and treatment, risk reduction, and self-management<sup>2-5</sup>.

Self-management focuses on maximizing function through biological, psychological, and social interventions, and encompasses engaging in various activities and daily life organization in order to manage one's condition and symptoms, protect and promote one's health and wellness, and maintain as active a life as possible<sup>6,7</sup>. In response to the call for a chronic disease management strategy approach to dementia, 'living well' with dementia and 'supported selfcare' frameworks are being adopted by dementia advocacy and volunteer organizations. With early interventions becoming increasingly recognized as essential for individuals with dementia, more and more attention is being directed towards health and wellness promotion as a critical component for 'living well' with dementia, particularly for individuals in the earlier stages of the disease<sup>8</sup>. For example, the Alzheimer's Society of Canada and the Alzheimer's Foundation of America recommend a healthy diet, mental exercise, physical activity, socialization, participating in spiritual and religious activities, stress management, and other lifestyle choices, such as controlling hypertension, as valuable self-management strategies for maintaining overall health for those living with dementia<sup>9,10</sup>.

It is thought that health and wellness promotion information provided soon after dementia diagnosis, along with enhanced coping skills, may lead to health behavior changes that will prevent excess disability or premature loss of function and



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institutionalization. Not only do health and wellness promotion interventions have the potential to affect overall function, they may also affect community life<sup>11</sup>. To date, very little has been published regarding self-management for people with dementia. Participating in support groups that emphasize social activities and sharing experiences with peers, as self-management strategies, have been shown to be beneficial for people with dementia<sup>12</sup>. A 2011 report on selfmanagement found that people with dementia do engage in a variety of physical activities, such as hockey, golf, biking, hiking, skiing, running, fitness courses, swimming, and walking, and cognitive exercises including playing card games, computer games, and attending memory programs at the local Alzheimer's society<sup>13</sup>. Despite the shift to selfmanagement and encouraging health and wellness promotion behaviors in people with dementia, there is a paucity of research and very little is known about the types of behaviors those with dementia engage in to self-manage their health and wellness. The purpose of this exploratory study was to (1) describe the health- and wellness-related self-management behaviors patients attending a rural and remote memory clinic engage in and (2) examine the relationship between engaging in health and wellness behaviors and psychological function, neuropsychological function, independence in daily activities, and physical function (gait and balance).

# Methods

An exploratory mixed-methods study of a cross-sectional sample was used to examine health and wellness behaviors, and the relationship between health and wellness behaviors, specifically engaging in exercise and nutrition (eating well), and measures of function, depression, memory, and gait and balance.

#### Sample

The sample included 260 patients referred to the Rural and Remote Memory Clinic (RRMC), Saskatoon, Saskatchewan, Canada. The RRMC is an interdisciplinary (neurology, neuropsychology, nursing, physical therapy), one-day, 'onestop' clinic, which has been in existence since 2004. The

RRMC integrates telehealth for assessment and follow-up and serves community-dwelling rural and remote residents, specifically those living more than 100 km from tertiary care<sup>14,15</sup>. Referrals to the RRMC are made by family physicians to the neurologist, but may be initiated by a family member or any member of the health team<sup>14</sup>. The clinic follows a family-centered approach. At least one caregiver attends the RRMC with the patient to provide information on the patient's history and daily functioning, to participate in joint interviews, and to complete questionnaires if and as required<sup>14</sup>. The RRMC uses a multidisciplinary approach and established guidelines for the clinical diagnosis of dementia. The added value of this multidisciplinary assessment is the ability to differentiate among the dementia subtypes<sup>16</sup>. The interprofessional assessment includes up-to-date blood work, neuropsychological CT head scan, assessment, physiotherapy assessment, neurology assessment, clinical history, and an extensive caregiver interview<sup>14</sup>.

All patients in the sample were diagnosed with a cognitive impairment resulting from single-domain or multi-domain amnestic (aMCI), non-amnestic mild cognitive impairment (non-aMCI), dementia due to Alzheimer's disease (AD), or non-AD dementia (various etiologies). Not surprising, almost half of the sample (43.8%) had a diagnosis of AD. Summaries and frequencies of diagnoses of the patient sample are shown in Table 1.

#### Measures

Patient and caregiver questionnaires and assessments administered at the RRMC clinic day appointment<sup>14</sup> provided the sociodemographic data including age, sex, years of formal education, and health and wellness behaviors and lifestyle data. Regarding exercise and nutrition (eating well) behaviors, patients answered two specific questions: 'How many times per week do you exercise for a minimum of 20 minutes?' and 'Do you follow the diet requirements outlined in the Canada Food Guide [*Canada's Food Guide to Healthy Eating*]?'<sup>17</sup>. *Canada's Food Guide to Healthy Eating*] provides general information about the number of servings from each food group – grain products (5–12 servings),



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vegetables and fruit (5–10), milk products (2–4), and meat and alternatives (2–3) that Canadians should consume<sup>17</sup>. *Canada's Food Guide to Healthy Eating* has a total diet approach to choosing foods. The total diet approach aimed to meet both energy and nutrient requirements, recognizing that energy needs vary based on age, body size, activity level, sex and specific conditions, such as pregnancy and breastfeeding<sup>17</sup>. Regarding psychological health and wellbeing behaviors, patients answered an open-ended question: 'How do you maintain your psychological health?'

Patients completed questions from the Centre for Epidemiologic Studies of Depression Scale<sup>18</sup>. Patients also completed a neuropsychological battery. The ability to alternate attention was measured with the Trail Making Test Part B<sup>19</sup>. The ability to inhibit an automatic response was measured with the Stroop interference test<sup>20</sup>. Cognitive flexibility with speeded retrieval of language-based knowledge was measured using animal naming, a semantic fluency task<sup>21</sup>, and a phonemic fluency task<sup>22</sup>. The clock drawing test measured visual construction, abstraction, and inhibition<sup>23</sup>. Finally, the index scores from the Repeatable Battery for the Assessment of Neuropsychological Status (RBANS)<sup>24</sup> were analyzed, which included a measure of attention and speed of mental processing, visuospatial and visuoconstructional abilities, language abilities of naming and generative fluency, and immediate and delayed memory for word lists and a short story, and delayed recall of a complex figure. The Mini-Mental Status Exam(MMSE)<sup>25</sup> is used as a screening measure in the RRMC, and is completed at the beginning of the neuropsychological battery. Caregivers who accompanied patients to the clinic reported on the patients' ability to function independently in daily life (instrumental activities of daily living) with the Functional Assessment Questionnaire<sup>26</sup>. The Berg Balance Scale (BBS)<sup>27</sup>, a 14item task-oriented test that assesses balance abilities, was quantified from the physical therapy assessment. Table 2 further describes each of the questions and measures above, scoring methods, and cut-offs as applicable.

#### Data analysis

Patients were grouped based on their diagnoses. As well as an AD dementia group, a heterogeneous group of non-AD

dementia (as per the diagnostic breakdown in Table 1) and two groups of patients with MCI were created - one for aMCI, which is a risk factor for dementia due to AD, and one for non-aMCI. Questionnaire data were analyzed using descriptive statistics and correlational analyses. Bivariate associations were assessed using point-biserial and Spearman's correlations. It was postulated that patients' number of chronic conditions would pose a confound with these associations and so the number of chronic conditions across the four diagnostic groups - aMCI, non-aMCI, dementia due to AD and non-AD dementia (Table 3) - was examined. As can be seen in the first row of Table 4, these small associations were statistically non-significant; therefore, the number of chronic conditions was not considered a covariate in any analyses. Due to small cell sizes in the two MCI groups, inferential analyses were only conducted for the two dementia groups (AD and non-AD dementia).

Coding for the questions 'How many times per a week do you exercise for a minimum of 20 minutes?' and 'Do you follow the diet requirements outlined in the Canada Food Guide?' are reported in Table 2. Canada's Food Guide to Healthy Eating was updated in 2007, 3 years after the implementation of the RRMC, thus the authors analyzed the cases where responses were provided to the Canada's Food Guide to Healthy Eating<sup>17</sup> question. Associations between selfreported exercise with psychological and neuropsychological, functional, and gait and balance variables were assessed for the AD versus non-AD dementia diagnostic groups. Associations between self-reported adherence to Canada's Food Guide to Healthy Eating<sup>17</sup> with psychological, neuropsychological, functional, and gait and balance were also assessed for the AD and non-AD groups. To examine the self-reported strategies used to maintain psychological health, responses to this open-ended question were analyzed thematically. Thematic analysis encompasses searching across a data set to find and analyze repeated patterns (themes), and does not derive from nor is tied to a particular epistemological or theoretical position<sup>28,29</sup>. Specifically, the authors used a semantic approach whereby the themes are identified within the surface meaning of the data, without looking beyond what is written<sup>29</sup>.





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#### Table 1: Patient sample: frequency of diagnosis based on best-practice interprofessional assessment

Diagnosis	N
Amnestic mild cognitive impairment, single or multiple domains	23
Non-amnestic mild cognitive impairment, single or multiple domains	23
Dementia due to Alzhemier's disease	114
Non-Alzhemier's disease dementia	100
Vascular dementia	14
Mixed vascular dementia	27
Frontotemporal lobar degeneration – frontal variant	14
Frontotemporal lobar degeneration – progressive non-fluent	5
Frontotemporal lobar degeneration – semantic dementia	10
Diffuse Lewy body disease	16
Subcortical pathologies (Huntington's or Parkinson's disease)	3
Dementia due to a general medical condition or not otherwise specified	11

#### Table 2: Questions and measures used for data collection at the Rural and Remote Memory Clinic

Question or measure	Description and scoring
How many times per week do you exercise for a	Patients enter the number of times per week they exercise for a minimum of 20 minutes.
minimum of 20 minutes?	For analysis, this question was coded as:
	0 = exercise less than three times per week for 20 minutes
	1 = exercise three or more time per week for 20 minutes
Do you follow the diet requirements outlined in	Patients enter their response to the question.
the Canada Food Guide (ie do you make daily	For analysis, this question was coded as:
choices from each of the following food groups:	0 = No requirements met; poor eating habits (poor)
grain products (five to 12 servings)	1 = Minimum requirements met: fair eating habits (fair)
vegetables and fruits (five to 10 servings),	2 = Most requirements met; good eating habits (good)
milk and milk products (two to four servings),	3 = All requirements met; excellent eating habits (excellent)
meat and alternatives (two to three servings)?	
How do you maintain your psychological health?	Patients enter their response to this open-ended question.
, , , , , , , , , , , , , , , , , , ,	Responses were thematically analyzed.
Centre for Epidemiologic Studies of Depression	A 20-item self-report questionnaire developed to identify depression symptoms or psychologic
(CES-D) Scale	distress, including depressed mood, feelings of guilt and worthlessness, feelings of helplessness ad
	worthlessness, psychomotor retardation, loss of appetite, and sleep disorders. Participants answer
	questions about the regularity and length of the depressive moods, thoughts or feelings in the past
	week.
	Each question uses a 0 ('rarely or none of the time') to 3 ('most or all of the time') response scale,
	except for the four positive questions (questions 4, 8, 12 and 16 are worded positively and their
	scores are reversed by subtracting the score from 3).
	Question scores are then summed to provide an overall score ranging from 0 to 60. A higher score
	indicates greater depression, and scores of 16 or more are indicative of depression.
Trail Making Test Part B	Examines ability to alternate attention.
S	The Trail Making Test B consists of 25 circles distributed over a sheet of paper. In Part B, the
	circles are numbered 1 to 13 and lettered A to L. The patient is asked to draw lines to connect the
	circles in an ascending pattern, but with the added task of alternating between the numbers and
	letters (ie 1-A-2-B-3-C, etc.).
	Scoring is reported as the number of seconds required to complete the task (errors are captured by
	increased time to complete), with higher times to complete indicative of greater impairment.
Stroop interference	Examines selective attention and the ability to inhibit an automatic response. Words that are
su sop interference	names of colours are shown to a patient. The words are printed in a color of ink different from the
	color name the word represents.
	For this version of the Stroop, the score is the number of correct responses within a specific
	timeframe, with fewer items correct indicating greater impairment.
	undranic, with lewer items correct indicating greater impairment.



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#### Table 2: cont'd

Question or measure	Description and scoring
Semantic fluency (animal naming)	Examines cognitive flexibility with speeded retrieval of language-based knowledge.
	The patient is given the following instructions: 'Tell me the names of as many animals as you can
	think of, as quickly as possible.'
	Scoring is reported as number of animals correctly named in 60 seconds, with lower scores
	indicating higher impairment.
Phonemic fluency task	Examines cognitive flexibility with speeded retrieval of language-based knowledge.
	The patient is asked to generate words beginning with a specific letter.
	Scoring is reported as number of words correctly generated with one of three specific letters in 60 seconds, with lower scores indicating higher impairment.
Clock drawing test	A test of cognitive function that can indicate constructional apraxia, left unilateral spatial neglect,
8	conceptual difficulties and disturbance of visuospatial skills.
	Scoring comprises omissions of numbers, errors in placing numbers, rotations, perseverations,
	switching numbers, and the spacing between the numbers.
	A lower score indicates a higher level of impairment.
Repeatable Battery for the Assessment of	A neurocognitive battery with four alternate forms. It contains 12 subtests: a list learning test,
Neuropsychological Status (RBANS)	immediate memory for a brief story, a copy of a complex figure, a judgement of line orientation
	task, a naming task, a semantic fluency task, a speeded digit symbol matching task, a test of
	forward digit span, a delayed free recall of the list learning test, a recognition task for the list
	words, a delayed free recall of the story, and a delayed recall of the complex figure.
	The raw scores from the 12 subtests are scaled together to create five index scores measuring the
	domains of immediate and delayed memory, attention, language, and visuospatial skills. These are
	summed for conversion to a total scale score. Lower scores indicate higher level of impairment.
Mini-Mental Status Exam (MMSE)	A screening measure in the Rural and Remote Memory Clinic.
	The MMSE comprises 11 items that evaluate orientation to time, place, recall ability, short-term
	memory, and arithmetic ability.
	The questions are scored by summing the points for each item with a maximum score of 30. A
	score of 24 is indicative that further testing is required.
Functional Assessment Questionnaire	An informant-based measure of functional abilities. The informant rates the patient on ten
	complex higher-order activities from 3 (dependent) to 0 (normal).
	A total score is computed by summing the scores across the 10 items. Scores range from 0 to 30.
	A cut point of 6 (dependent in two or more activities) is indicative of functional problems, and
	may be used to distinguish those with dementia from those without dementia.
Berg Balance Scale (BBS)	Comprises 14 items, that BBS assesses static and dynamic activities of varying difficulty.
	Each item is scored on a 0 to 4 scale, resulting in a maximum score of 56 total score.
	Total scores of less than 45 are indicative of a higher fall risk in the elderly.

Written responses were read and re-read by two authors individually to capture theme frequencies and cooccurrences. Similarities, patterns, and consistency of the themes were reviewed; this process was repeated until consensus was reached regarding the themes, and the theme reflected the written responses as a whole. Last, the qualitative themes were quantized to transform them into quantitative data<sup>30</sup>. Qualitative data were first reduced into items (themes) intended to mean only one thing, so that the items could then be represented numerically<sup>30</sup>. Specifically,

the developed themes were tallied using descriptive analyses to determine the frequency counts, and then these tallies were summarized into general categories.

#### Ethics approval

The research was approved by the University of Saskatchewan Behavioural Research Ethics Committee (BEH #03-12-19).



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None         2           1         3           2         12           3         18	6 2 6	0	2 0
2 12	2	0	0
2 12	6	1	2
3 18	0	1	2
	7	4	2
4 17	10	6	4
≥5 51	56	12	13

Table 3.	Frequency	of chro	nic co	nditions	hy diagr	nostic group
Table 5.	riequency	or cm	June co	nuntions	Dy ulagi	iostic group

AD, Alzheimer's disease. aMCI, amnestic mild cognitive impairment

# Results

Participants were aged between 44 and 97 years (mean=74.07, standard deviation (SD)=9.18) and had between 0 and 20 years of formal education (mean=10.48, SD=3.30). Almost two-thirds (61.5%) of the sample was female. Mini-Mental Status Exam scores ranged from 5 to 30 (mean=23.25, SD=4.50).

For those with dementia due to AD the mean MMSE was 21.58 (SD=4.07), and for those with non-AD dementia the mean MMSE was 23.08 (SD=4.65). For those with aMCI, the mean MMSE was 27.22 (SD=1.86) and for those with non-aMCI the mean MMSE was 27.95 (SD=1.56). As expected, there was a statistically significant difference between groups, with the dementia groups having lower MMSE scores than MCI groups (F(3237)=24.14),  $p \le 0.001$ ). Mean RBANS total scores ranged from 45 to 103 (mean=66.51, SD=13.07). For the AD dementia group the mean RBANS score was 61.16 (SD=10.09) and for the non-AD dementia group the mean RBANS score was 66.03 (SD=13.73). For the aMCI group the mean RBANS score was 77.41 (SD=7.67) and for the non-aMCI group the mean RBANS was 78.79 (SD=12.26). Again, as expected, there was a significant difference between groups (F(3182)=20.23, p<0.001, with the dementia groups having lower RBANS scores than MCI groups.

Table 3 shows the frequency counts of chronic diseases for the aMCI, non-aMCI, dementia due to AD and non-AD dementia diagnostic groups. Almost half (45.8%) of those with dementia due to AD reported having five or more chronic conditions. For those with non-AD dementia, 56% reported having five or more chronic conditions. A similar pattern was seen with the MCI diagnostic groups, with 52.2% of those with aMCI reporting five or more chronic conditions and 56.2% of those with non-aMCI reporting five or more chronic conditions.

For the non-AD dementia diagnostic group, associations between exercise and tests of neuropsychological function were trivial or small and statistically non-significant, likely due to the heterogeneity of the group. In contrast, for the group with AD, engagement in exercise for 20 minutes for three or more times a week was moderately associated with improved performance on the Stroop interference test and better balance, as indicated by BBS scores. For both the AD and non-AD dementia groups, engagement in regular exercise was not significantly associated with caregivers' reports of patients' ability to function in daily life (small effect), and there was a trivial and statistically non-significant association between exercise and symptoms of depressed mood.

Associations between nutritional practices and the neuropsychological, mood, and functional variables were statistically non-significant for the non-AD group. For the



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group of patients with an AD diagnosis, better nutritional practices were associated with improved scores on the RBANS language subtests (naming and semantic fluency subtests) and the total RBANS score, and better clock drawing and phonemic fluency test scores. Although the sample size was small, the moderate association between the BBS was significant and better nutrition practices was associated with better balance, as measured by the BBS (Table 4).

Table 5 illustrates exercise and nutrition habits for the aMCI, non-aMCI, dementia due to AD and non-AD dementia diagnostic groups. Except for the AD group, more than half of the other groups - aMCI (57.1%), non-aMCI (60%) and non-AD dementia (52.9%) - reported exercising for 20 minutes less than three times per week. Less than half (42.7%) of the AD group reported exercising for 20 minutes less than three times per week. Importantly, over a third (39.4%) of the total sample reported not exercising at all on a weekly basis and the vast majority (97.5%) reported weekly exercise less than 150 minutes weekly, the minimum amount for adults and older adults according to the Canadian Society for Exercise Physiology<sup>31</sup>. Of the 229 respondents with complete questionnaire data, about three-quarters (74%) of individuals reported they met most or all of the Canada's Food Guide to Healthy Eating dietary recommendations<sup>17</sup>. Threequarters (75.2%) of the AD group, 73.8% of the non-AD dementia group, 73.9% of the aMCI group and 66.7% of the non-aMCI (60%) group reported meeting most or all of the Canada's Food Guide to Healthy Eating dietary recommendations<sup>17</sup>.

More than two-thirds (71%) of respondents indicated they were engaged in wide variety of activities to maintain their psychological health (Table 6). Many of the 187 participants who reported engaging in activities to maintain their psychological health reported more than one activity. However, a very small number (2.1%) reported engaging in a combination of physical activities, social activities, and mentally stimulating activities. About 20% of the sample reported engaging in passive activities or did not engage in any activities to maintain their psychological health. The types of activities the sample reported engaging in to maintain psychological health are depicted in Figure 1.

# Discussion

This exploratory study examined the health and wellness behaviors of patients attending a rural and remote memory clinic and the relationship between engaging in health and wellness psychological behaviors and function, neuropsychological function, independence in daily activities, and balance. Almost half of those with dementia due to AD, and over half of those with non-AD dementia and aMCI reported having five or more chronic conditions. Considering risk of dementia increases with increasing age, with prevalence increasing from 8% in those 65 years and older to 34.5% in those 85 years and older<sup>32</sup>, and that the majority of older persons experience multiple comorbid conditions and diseases<sup>33</sup>, this result is not surprising. However, there are implications for chronic disease approaches and selfmanagement strategies for those with dementia. Those with dementia may not only have to deal with their dementia diagnosis, but may have self-management needs related to multiple co-existing comorbid chronic conditions that need to be considered in any health and wellness promotion intervention or program.

The Alzheimer's Society of Canada and the Alzheimer's Foundation of America recommend the following selfmanagement strategies for maintaining overall health for those living with dementia: a healthy diet; mental exercise; physical activity; socialization; participation in spiritual and religious activities; stress management; and other lifestyle choices, such as controlling hypertension<sup>9,10</sup>. The majority of the sample of rural and remote dwelling people with dementia reported participating in a variety of pleasurable activities to maintain psychological health and report good nutrition habits. However, only a very small percentage reported participating in a combination of physical activities, social activities and mentally stimulating activities, about a tenth of the sample was not actively engaged in addressing



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their psychological health at all or reported engaging only in passive activities, and about a quarter reported meeting minimal or none of *Canada's Food Guide to Healthy Eating*<sup>17</sup> recommendations. The importance of cognitive stimulation in the prevention and treatment of early-stage memory loss<sup>34</sup>, and the importance of socializing for addressing psychological health<sup>12</sup>, has been reported in the literature. Because of the cross-sectional sample and the nature of the data collection and analyses, it was not possible to discern why these individuals were not engaging in positive, health promoting behaviors, and this requires further investigation. In addition, the findings suggest that more targeted strategies need to be developed in the RRMC to ensure patients and caregivers are made aware of the importance of engaging in a range of health and wellness promotion activities.

Interestingly, reporting good nutritional habits was associated with better neuropsychological function, specifically total RBANS scores, RBANS<sup>23</sup> language sub-test scores, clock drawing test scores and phonemic fluency scores, and BBS scores for the AD subsample. There is a dearth of research related to nutrition in the earlier stages of dementia; however, authors have reported that education regarding nutrition may have a positive effect on patients with respect to cognitive function<sup>35</sup>, and meeting nutritional needs is an important aspect of caring for people with dementia, in all stages including the early stage of disease<sup>36</sup>. Epidemiological studies suggest that nutrition can modify the risk of dementia onset<sup>37,38</sup>. A diet high in vegetables, legumes, fruits, cereals, and unsaturated fatty acids has been found to be associated with decreased risk of developing mild cognitive impairment and of the conversion of mild cognitive impairment to AD<sup>39</sup>, and there is evidence that nutritional interventions can decrease brain atrophy in people with mild cognitive impairment<sup>40</sup>. Unfortunately, the subsample of aMCI and non-aMCI was too small for further inferential analyses to examine associations between reported nutritional habits and neuropsychological function and balance. Despite the growing evidence about the benefits of healthy eating, the research on nutrition in people with dementia has tended to focus on those in the later stages of the disease. Little attention, until more recently, has been directed towards the

importance of good nutrition for those in the earlier stages of dementia. This warrants further investigation, particularly the benefits of healthy eating in the early stages as part of 'living well' with dementia.

Although positive benefits of exercise were found in those with AD, half of the sample who reported on exercise (all subgroups) reported exercising less than three times per week for 20 minutes, and many reported not exercising for the recommended time for health benefits<sup>31</sup>. In addition, over half of the aMCI subgroup reported exercising less than three times per week for 20 minutes. A feasibility study of highintensity aerobic exercise in 33 individuals with aMCI found that women in the aerobic exercise group demonstrated improved performance on multiple tests of executive function, and for men aerobic exercise had a favorable effect only on Trail Making Test Part B performance<sup>41</sup>. The authors suggest that aerobic exercise plays a protective role by attenuating progression of cognitive symptoms in MCI<sup>41</sup>. Similarly, a 12-month randomized controlled trial of moderate-intensity walking for adults with MCI found that attention and memory improved for women; for men, only the most adherent had improved memory, but attention was unchanged<sup>42</sup>.

Rural residents often have fewer destinations within walking distance, and a lack of well-maintained sidewalks can create a fear of injury that discourages walking or biking<sup>43</sup>. The built environment in rural and remote areas can also positively or negatively influence individuals' attitudes towards health and health behaviors44. A qualitative examination of physical activity in older adults living in rural areas concluded that built environment characteristics (eg well-maintained sidewalks, accessible destinations, and an aesthetically pleasing environment) were each associated with increased walking and biking<sup>45</sup>. Whether or not the built environment was an important factor related to physical activity and exercise participation for this RRMC patient sample warrants further investigation.



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Table 4: Associations between lifestyle variables of regular exercise (higher score coded for more exercise) and nutrition habits (higher score coded for reported greater adherence to *Canada's Food Guide to Healthy Eating*) for neuropsychological, functional, physical, and mood measures for the dementia due to AD or non-AD dementia

groups

Measure	AD exercise	Non-AD exercise	AD nutrition	Non-AD nutrition
	$r_{ m pb}$	$r_{\rm pb}$	r <sub>pb</sub>	$r_{\rm pb}$
	n	'n	'n	'n
Number of chronic conditions	-0.119	-0.164	0.166	-0.180
	89	73	101	84
RBAN Immediate memory index	0.042	-0.093	0.093	0.051
	82	60	93	67
RBAN Visuospatial/Constructional index	-0.058	0.091	0.177	0.126
*	77	55	88	60
RBAN Language index	0.087	0.075	0.266**	0.155
	83	60	94	67
RBANS <sup>TM</sup> Attention index	0.166	-0.041	0.168	-0.021
	77	53	86	57
RBAN Delayed memory index	0.027	-0.064	-0.015	0.129
	81	58	91	64
RBAN Total scale	0.103	-0.057	0.239*	0.117
	72	50	79	53
Stroop test interference	0.343*	0.080	0.182	0.117
*	50	37	54	41
Trail Making Test Part B	0.101	-0.032	0.206	0.189
0	53	45	60	48
Clock drawing test	0.042	-0.125	0.238*	-0.145
c	83	63	94	69
Phonemic fluency	0.093	0.119	0.223*	-0.053
	81	61	92	69
Semantic fluency	-0.015	0.096	0.031	-0.041
	82	63	92	71
Functional Assessment Questionnaire	-0.145	-0.224	-0.078	0.047
-	88	73	101	84
	26	21	26	22
Berg Balance Scale	0.366**	0.170	0.275*	0.056
~	60	48	66	52
Centre for Epidemiologic Studies of Depression	-0.024	-0.077	-0.180	-0.236
Scale Total Score	82	62	92	69

\*p<0.05; \*\*p<0.01

RBANS, Repeatable Battery for the Assessment of Neuropsychological Status

Currently, there are no published guidelines specifically targeting people with dementia, and particularly those in the earlier stages of dementia. The data suggest there is a small but significant association between exercising three or more times per week for at least 20 minutes and better balance when measured objectively, and better Stroop interference scores in the subsample with AD. Both of these findings are consistent with literature in older adults without dementia. Older adults who exercise are more likely to have better balance<sup>46</sup>, and a beneficial impact of physical activity and exercise has been found on older adult executive functioning<sup>47</sup>. According to the Canadian Society for Exercise Physiology's *Canadian Physical Activity Guidelines*, older adults (65 years and older) should engage in at least 150 minutes of moderate-to-vigorous-intensity physical activity per week<sup>31</sup>. It is also recommended that Canadians should try to exceed the minimum activity thresholds, as there are greater health benefits with more variety, intensity and duration of the physical activity<sup>31</sup>.



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 Table 5: Frequency of exercise and nutrition health-related behaviors of the patient sample

Health-related behavior	AD	Non-AD	aMCI	Non-aMCI
	n	Dementia	n	n
	%	n	%	%
		%		
Exercise (N=203 with complete data)				
Reports exercising less than three times per week	38	40	12	12
for at least 20 minutes	18.7%	19.7%	11.8%	11.8%
Reports exercising three or more times per week	51	33	9	8
for at least 20 minutes	25.1%	16.3%	4.4%	3.9%
Nutrition ( <i>N</i> =229 with complete data)				
Reports meeting some or all of Canada's Food	76	62	17	14
Guide recommendations (good to excellent				
nutrition)				
Reports meeting none or minimum Canada's	25	22	6	7
Food Guide recommendations (poor to fair				
nutrition)				

AD, Alzheimer's disease. aMCI, amnestic mild cognitive impairment.

# Table 6: Frequency of patients' responses to the open-ended question 'How do you maintain your psychological health?' (N=187)

Activities	n
Engage in physical activities, social activities, and mentally stimulating activities	4
Engage in physical activities, and social activities or mentally stimulating activities	29
Engage in physical activities	17
Engage in social activities and mentally stimulating activities	16
Engage in social activities	38
Engage in mentally stimulating activities that are solitary	33
Engage in solitary hobbies that may or may not be mentally stimulating	13
Try to 'keep busy' or focus on their medical health	16
Watch television or engage in other passive activities	10
Reported that they do nothing to address their psychological health	11

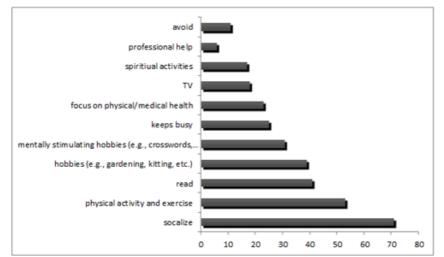


Figure 1: Tally of all the activities reported in response to the open ended question 'How do you maintain your psychological health?' (Some of the 187 respondents reported up to four different activities, and all activities were included in these tallies.)



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Similarly to good nutrition, physical exercise appears to reduce risk of dementia<sup>48</sup>. Although few high-quality randomized control trials exist regarding exercise interventions for people with dementia<sup>49</sup>, best-practice guidelines based on cumulative evidence suggest that individualized exercise programs may improve fitness, cognition, and day-to-day function for people with mild to moderate dementia<sup>50</sup>. In addition, there is evidence that physical activity at an intensity level adapted to a person's overall physical capacities should be promoted as part of a 'healthy lifestyle' for older individuals with memory loss<sup>51</sup>. The exercise-related findings, as well as the psychological health findings, speak to the need for additional education for the RRMC patients related to 'living well' with dementia and the need for more formalized self-management programs specifically targeting those living in rural and remote areas. Health is a considered 'a complete state of physical, mental and social well-being and not merely the absence of disease or infirmity'52. Early diagnosis and interventions are critical elements of effectively managing people with dementia, and promoting health and wellness behaviors in people with dementia has become recognized as a key component of the overall management of this patient population. Health and wellness promotion, prevention and early intervention activities have the potential to not only reduce the prevalence and impact of a number of chronic diseases that individuals with dementia may have, but may also prevent or slow the onset and progression of dementia. As dementia is now recognized as a chronic disease, similar to those with other chronic diseases, engaging in 'living well' activities may help those with dementia remain active and may positively influence function and quality of life.

There is a dearth of information and research related to health and wellness promotion for people with dementia, and services for people in early stages of dementia are often limited; as a result these individuals frequently become isolated and stigmatized<sup>53</sup>. A 2007 expert panel consensus report found that support groups for older adults in the early stages of dementia comprised poorly designed research designs and had weak scientific evidence<sup>34</sup>. Well-designed

self-management interventions based on strong evidence may address the care gap and may be a possible solution for providing support in the early stages of disease<sup>54</sup>. The goal of self-management is to improve quality of life, and selfmanagement focuses on providing patients with the skills to manage their lives in the face of chronic illness<sup>6,7</sup>. Selfmanagement programs typically include information about common problems faced by individuals with a chronic condition, and address topics such as nutrition, exercise, managing medications, psychological health, and management of symptoms. However, the nature of dementia is considered a barrier for self-management and highlights the need for early diagnosis. A majority of people with dementia considered that information provided following diagnosis was aimed predominantly at their carers, leading to feelings of powerlessness and helplessness<sup>55,56</sup>. The findings from this emerging work can help inform memory clinics, such as the RRMC, about the best approaches to providing important health and wellness information to patients and caregivers, and can assist with the design of targeted education and selfmanagement programs.

### Conclusions

This study found that rural and remote dwelling people with dementia and mild cognitive impairment attending a memory clinic do participate in a variety of pleasurable activities to maintain psychological health and report good nutrition habits. However, a majority do not engage in recommended amounts of weekly exercise, and only a few participate in a combination of physical activities, social activities and mentally stimulating activities. The effects of the rural environment, as potential barriers to engaging in health and wellness behaviors, should be further explored. Engaging in exercise and good nutritional habits were found to have beneficial effects in the sub-sample of patients with AD. Patients and their caregivers attending the RRMC may require additional education and information and more targeted strategies regarding beneficial health and wellness

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promoting behaviors related to their diagnosis and concurrent comorbid conditions.

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