# Perspectives of Persons with Memory Changes and Care Partners for Reducing Barriers to Community Wellness Programs

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# ABSTRACT

Existing research demonstrates that community-dwelling persons with memory changes (PWMC) (including dementia) and care partners (CPs) benefit from nutrition and exercise, especially for frailty and sarcopenia prevention. However, needs and preferences for wellness programs are still unknown. The objective of this eight-month online survey study was to explore PWMCs' (n=24) and CPs' (n=46) perspectives on nutrition/exercise barriers and their preferences for program content and format to inform a community wellness program. PWMC self-reported, while CPs reported for themselves and their cared-for person with dementia (CPWD). Descriptive analyses revealed that 78% of PWMC, 64% of CPs, and 39% CPWDs were interested in a wellness program that combined nutrition and exercise. Content preferences varied (e.g., 45% of CPs were interested in yoga/Pilates, but only five percent of CPWD were interested). Over half of the participants preferred online delivery for nutritional information (55% PWMC, 54% CP). Group fitness was popular for exercise among all groups. In addition, participants prioritized attending as dyads twice or more per week, closeness to home, reasonable cost, knowledgeable instructors, a fun social environment, and beginner-friendliness. To conclude, greater consideration for flexibility in program content and format will help to meet these diverse needs and preferences.

# INTRODUCTION

Globally, dementia is one of five major causes of death.<sup>1</sup> Healthy diet and exercise are associated with improved well-being of persons living with dementia, mild cognitive impairment (MCI), or other memory changes (together referred to as persons with memory changes (PWMC)).<sup>2'3</sup> Almost 60% of PWMC and one-third of their paid or family/friend care partners (CPs) are at nutrition risk, which is associated with higher levels of required care and hospitalization.<sup>4</sup><sup>5</sup> Nutritional concerns for PWMC include, but are not limited to weight loss, forgetting/refusing to eat, dysphagia, and appetite loss, which can lead to sarcopenia and frailty.617 Foodrelated activities comprise a large proportion of CPs' care burden due to stress, tension, anxiety, and negative attitudes from pressure to provide nutritious meals for their loved one with dementia.<sup>8-10</sup> Furthermore, many older adults today are inactive, including those with memory changes<sup>11</sup>, yet, both aerobic and resistance exercise improve functional abilities, cognitive function, mental health, and body composition, regardless of cognitive status.<sup>12-14</sup> Exercise is a key strategy in preventing sarcopenia and frailty<sup>15,16</sup>, and programs that promote wellness and reduce

frailty risk in PWMC are crucial.<sup>17</sup> Establishing a community program that unites exercise, nutrition, and social well-being can be beneficial for PWMCs and their CPs. Moreover, understanding CPs' and PWMCs' barriers to and preferences for wellness programs will help develop interventions that are likely to be adopted in practice.<sup>18</sup> This study explored perspectives on barriers for exercise/wellness programs, challenges in eating well and being active, and wellness program content and format preferences to inform a future community program.

# METHODS

### Population

A convenience sample of persons self-identifying as either a PWMC (dementia, MCI, or memory changes) or family or friend CP (unpaid, informal) was recruited using snowball and convenience sampling, a method used to identify hard-to-reach groups.<sup>19</sup> Notice of the online surveys was disseminated through stakeholders (e.g., the Alzheimer Society of Canada, Active Aging Canada, the Research Institute for Aging, and a Neurological Patient Database), Twitter, member email blasts, newsletters, and website postings. Telephone or mail questionnaire options were provided. Ethics clearance was provided by an ethics review board at the University of Waterloo (ORE# 40753). A checkbox on the online form was used to indicate informed consent, and respondents were directed to the appropriate survey after identifying as a PWMC or a CP. As part of the ethics requirement, respondents could opt out of completing specific questions.

#### Design

After providing informed consent, respondents were directed to the appropriate survey: (1) PWMC survey and (2) CP survey wherein CPs provided answers for themselves and on behalf of their cared-for person with dementia (CPWD). A literature review informed questionnaire content (e.g., potential eating challenges) and program delivery modes (e.g., group vs. individual). Questions were vetted by the research team (authors of this study), doctorate-holding dementia experts, the Waterloo Regional Dementia Advisory Group, and researchers experienced in question construction.

For both PWMC and CPs, the survey consisted of three sections: demographics, food and nutrition, and exercise. The CP questionnaire also included items specific to their CPWD, which were consistent with questions from the PWMC version. The survey consisted of 24 (PWMC version) and 26 questions (CP

#### Analyses

Question responses were summed for analyses where appropriate by totalling frequencies for each response per multiple choice question. Program preference was categorized as nutrition only, exercise only, combined lifestyle approach, and not interested. Exercise types were grouped as: classbased exercise, other structured exercise, other independent exercise (including walking), and sport-like exercise. Statistical analysis was primarily descriptive; associations explored whether desired program content and format varied by age, gender, and length of time since diagnosis, using the Fisher-Freeman-Halton test with adjusted standardized residuals (ASRs) for post-hoc testing. Statistical significance was determined by ASR>[1.96]. To determine differences in the number of challenges between PWMC and CPWD, independent t-tests were used (p<0.05). Researchers employed Microsoft® Excel Version 16.35 and IBM SPSS® Statistics Version 26. Content of open response text responses were also analyzed by grouping together similar responses (e.g staff, lack of time, scheduling, etc.) into descriptive categories (e.g., ability levels, staff, etc.).

# RESULTS

Of the respondents, 46 were CPs (66%) and 24 were PWMCs (34%). All respondents completed online surveys, with the vast majority being completed (95%) in English. Response rates varied by question as participants were given the opportunity to opt out of any question. Table 1 summarizes demographic characteristics. About one-third (35%) of PWMC reported not being formally diagnosed with dementia/MCI, and 40% had been living with memory changes for under five years. Fortyfive percent of PWMC were women and most CPs were women (93%). Most CPWD had been formally diagnosed (93%) with dementia/MCI, with 63% having received a diagnosis within the past five years. Approximately 45% of PWMC self-reported daily exercise, while CPs reported that only 14% of CPWD exercised daily. For a few of the respondents, exercise and nutrition were reported as having worsened after being a CP (82% excellent/good nutrition rating before and 73% rating after becoming a CP). Open text responses indicated that this change in self-rated nutrition for these CPs was due to lack of time and decreased motivation to cook.

version); demographic-related questions included gender, ethnicity (multiple select), age, time of dementia diagnosis (or time living with memory changes), province/territory of residence, and living arrangements. These questions had multiple choice answers for participants to select. There was one open-ended question at the end of the questionnaire. Nutrition challenges were self-reported from a list of 15 items. Exercise frequency was evaluated using a five-point scale (never to daily). Respondents also selected barriers to participation in exercise and reported preferences for exercise type, location, and format. An open-ended question allowed respondents to describe their ideal community wellness program. Questionnaires were uploaded to Qualtrics XM Survey Software, pretested by six older adults from a local care home (including one CP), and published in English and French on May 27th, 2019 (closed January 31st, 2020). Data collected did not encompass challenges that people may have faced due to the pandemic or associated countermeasures. Our survey did not include any pandemic-specific questions (e.g., challenges exercising due to recreation facility closures). As there was no primary outcome, a sample size estimation was not conducted; limitations of this small sample are discussed after Results.

Nutrition challenges and exercise barriers for PWMC and CPWD are indicated in Figure 1a, 1b, and 1c. Interest in making meals (69%), increased or decreased appetite (69%), difficulty deciding what to make (65%), and weight change (65%) were the most frequent nutritional challenges for CPWD. Common challenges reported by CPs were: stress affecting motivation to eat well (19%), poor appetite (8%), lack of time for exercise (45%), low motivation (14%), and physical limitations (9%). PWMC reported weather (60%), limited mobility (47%), health condition(40%) and cost (40%) as key barriers to exercise, and difficulty in deciding what to eat/cook was their most common nutrition challenge (65%). Based on a Fisher-Freeman-Halton test, longer time since dementia diagnosis (more than five years, compared to being diagnosed within the past five years) was significantly associated with more overall reported nutritional or exercise challenges (p=0.049).

Respondent program preferences are indicated in Table 2. Over half of PWMC and CPs were interested in learning about nutrition, especially identifying nutritious food (53% and 52% respectively) and cooking easy, healthy meals (53% and 44% respectively). The preferred delivery method for nutrition education was online (PWMC 55%; CPs 54%). Print (50% PWMC, 38% CP) and in-person delivery with health professionals (40% PWMC, 38% CP) were also highly ranked. More than half of PWMC (58%) and most CPs (82%) were interested in being more active. Exercise preferences were diverse (e.g., 45% of CPs were interested in yoga or Pilates, but only 5% of CPWD reported this interest), although tretching, balance, walking, and lifting weights were most favoured across all three groups (PWMC, CPs, and CPWD). Many wanted to participate in an exercise group two or more times a week (61% of PWMC, 50% of CPs, and 47% of CPWDs, as reported by their CPs). PWMC were interested in group exercise classes (56%), although training with a friend (39%) or loved one (39%) was also popular. Similarly, most CPs (64%) preferred exercising with their CPWD. The most popular exercise locations for PWMC were fitness centres (61%), outdoors (44%) and community centres (44%). Ultimately, 78% of PWMC, 64% of CPs, and 39% CPWDs were interested in a wellness program that combined nutrition and exercise. Open-text responses provided further insight into participant views. As with all questions on the survey, completion of open-text responses was optional. PWMC reported that their mental/emotional health challenges could influence participation in a community program. Social aspects, including supportive, understanding, and friendly instructors and classmates, were considered essential. CPs commented on lack of time, noting that appropriate scheduling was essential due to other commitments (e.g., work, children, etc.). The ideal community wellness program would be: age-appropriate; cater to different ability levels; close to home; taught in small groups by kind, helpful staff; and offer

social opportunities. Some CPs indicated in this section that they would prefer a split program, where CPs and their CPWD learn different exercises.





			Cared-for			
			persons with			
	Dorsona with		dementia, as			
	memory changes (%)	Care partners (%)	partners (%)			
Time since formal dementia diagnosis						
>5 years	25 <sup>a</sup>		30 <sup>b</sup>			
<5 years	40		63			
Not formally diagnosed	35	—	7			
Age	10-	20.	4.4			
<60 years	40 <sup>a</sup>	32°	4ª			
60-79 years	45	61	44			
>80 years	15	7	52			
Gender	459	020	200			
Ethnicitae	43ª	930	390			
Canadian	75a	68¢	680			
European	15	50	64			
Province or territory	45	50	04			
Ontario	QOa	76f	_			
Another Canadian province	5	24				
Not from Canada	5	24 —	_			
Living situation	5					
With spouse	40a	_	_			
Alone	30	_				
With spouse and other family	15	_				
Other	10					
With other family member(s)	5					
Living situation	-					
Living with cared-for person	_	52 <sup>f</sup>	_			
Not living with cared-for person		48				
Urban or rural dwelling						
Urban	80 <sup>a</sup>	89°	_			
Perception of current nutrition						
Excellent	21g	33 <sup>h</sup>	23 <sup>i</sup>			
Good	47	40	19			
Average or fair	32	9	39			
Poor or terrible	—	18	19			
Exercise over the past month						
Every day or almost every day	45 <sup>a</sup>	50j	14 <sup>k</sup>			
A few times a week	55	29	54			
Once per week	0	8	18			
Never	0	13	14			
Self-reported nutrition status before	becoming a care par	tner				
Excellent/good	—	82 <sup>1</sup>				
Self-reported nutrition status after be	coming a care partn	er				
Excellent/good		73 <sup>h</sup>	—			
Self-reported exercise status before b	ecoming a care part	ner				
Excellent/good	—	64 <sup>1</sup>				
Self-reported exercise status after bed	coming a care partne	er				
Excellent/good	—	57 <sup>n</sup>				

#### TABLE 1. Demographic characteristics of respondents

— indicates that this question or option was not available Number of respondents: <sup>a</sup>20; <sup>b</sup>30; <sup>c</sup>28; <sup>d</sup>27; <sup>e</sup>Text box for respondents to complete with categories not mutually exclusive; <sup>f</sup>29; <sup>g</sup>19; <sup>h</sup>33; <sup>i</sup>26; <sup>j</sup>24; <sup>k</sup>22; <sup>1</sup>34



#### FIGURE 1a - Bar graph demonstrating food-related challenges of people with memory changes and cared-for people with dementia













programs			Cared-for persons			
	Persons with memory changes	Care partners	with dementia, reported by care partners (%)			
Nutrition topics of interest <sup>a</sup>	(/*)	(/*)	(/*)			
Identifying nutritious foods	53 <sup>b</sup>	52°	_			
Cooking easy, healthy meals	53	44				
Weight loss/gain	37	40				
Hydration	37	44				
Understanding nutrition labels	32	24				
Managing eating challenges	32	36				
Evaluating different diets	11	40				
Preferred method of nutrition educ	ation delivery <sup>a</sup>					
Online	55 <sup>d</sup>	54 <sup>e</sup>	_			
Print	50	38				
In-person presentations	40	38				
Health professional	55	35				
Not interested	5	31				
Interest in being more active						
Yes	58 <sup>b</sup>	82 <sup>f</sup>	18 <sup>f</sup>			
No	16	14	36			
Not sure	26	4	46			
Desired frequency of an exercise group						
Never	17 <sup>g</sup>	18 <sup>f</sup>	31 <sup>b</sup>			
<1 time per week	5	4	0			
Once per week	6	14	11			
≥2 times per week	61	50	47			
Other	11	14	11			
Exercises of interest <sup>a</sup>						
Stretching	79 <sup>h</sup>	73 <sup>f</sup>	50 <sup>f</sup>			
Balance exercises	68	68	41			
Lifting weights	53	36	23			
Walking	53	73	50			
Cycling	47	14	0			
Other strength exercises	32	55	36			
Yoga or Pilates	32	45	5			
Chair exercises	11	5	36			
Most important factors for choosing an exercise group/program <sup>a</sup>						
Closeness to home	56 <sup>g</sup>	73 <sup>1</sup>	64 <sup>r</sup>			
Knowledgeable instructors	56	50	32			
Reasonable cost	50	55	50			
Fun, social environment	44	64	59			
Beginner-friendly	28	36	59			

### TABLE 2. Respondent preferences for community food, nutrition, and exercise wellness programs

Exercise companions <sup>a</sup>			
With loved one	39 <sup>g</sup>	64 <sup>f</sup>	
Alone	33	14	
Not interested		23	
Group classes	56		
Friend	39		
Personalized individual training	33	<u> </u>	
Preferred exercise location <sup>a</sup>			
Fitness centre	61 <sup>g</sup>		
Outdoors	44		
Community centre	44		
Home or in my building	33	_	_

 indicates that this question or option was not available <sup>a</sup>Multiple select Number of respondents: <sup>b</sup>19; <sup>c</sup>25; <sup>d</sup>20; <sup>e</sup>26; <sup>f</sup>22; <sup>g</sup>18; <sup>h</sup>19

## DISCUSSION

This study sought to investigate the perspectives of communitydwelling PWMC and CPs (reporting for themselves and CPWD) on nutrition/exercise challenges and wellness program preferences to inform a community program. For future planning of wellness programs, many participants were interested in attending as dyads two or more times per week, at sites that were close to home, and were of a reasonable cost. Having dementia progression.<sup>25,26</sup> Specifically, as dementia progressively worsens, cooking- and food preparation-related abilities for PWMC may change and become more difficult. Therefore, it is important to bear in mind the variable experiences of individuals in their dementia journey, thereby highlighting the need for dynamic, adaptable, and tailored programming. Consistent with past research, major exercise

knowledgeable instructors and a fun, social, and beginnerfriendly environment were also important to respondents.

In previous research, community wellness programs (although not always specific to PWMC and CPs) have improved mobility, functional ability, knowledge, confidence, and competence with healthy eating.<sup>20-23</sup> There also exists reasonable literature on exercise programming and their specific benefits for PWMC. With group classes, attendees would further benefit from social engagement and peer support, which increases feelings of inclusion (building a sense of community) and can improve quality of life.<sup>24</sup> CPs may also experience health benefits from such a program, especially since our survey results identified that perceived exercise and nutrition status worsened upon becoming a CP.

Moreover, in line with published literature, PWMC, CPs, and CPWD (CP-reported) listed challenges with appetite, weight change, low fruit and vegetable intake, chewing and swallowing, and dietary restrictions.<sup>17/25</sup> All three groups of participants (PWMC, CPs, and CPWD) may find strategy-driven education sessions useful and applicable. Mealtime routines and relationships between PWMC and their CPs change with barriers reported by PWMC and CPWD herein were consistent with those identified by a systematic review, including bad weather, poor health and function, decreased energy, and loss



of motivation and resources.22 In the present study, we observed that most of the challenges experienced by respondents regarding both food/nutrition and exercise—were individual-level barriers (e.g., lack of time). With thorough planning, a wellstructured and effectively delivered program may be able to overcome challenges associated with health and function, motivation, and energy.

Exercise barriers were similar among CPs and PWMC, although insufficient time was more frequently reported among CPs. Insufficient time is a common barrier reported by older adults more broadly.23 The most important factors for choosing an exercise group or program had varied between the three groups, although similiarities can be found between them as well. As all three groups (PWMC, CP, CPWD) valued having a program that was close to home, programs at specialty sites (rehabilitation or healthcare sites, for instance) are likely not sufficient to meet their needs. Therefore, all three groups (PWMC, CPs, and CPWD) may benefit from programs that take place in their local facilities, such as community or recreation centres. PWMC and CPs also prioritized the cost of the program, indicating the need for affordable and accessible community programming. CP and CPWD valued a fun and social environment. A beginner-friendly environment was most important among CPWD. Thus, it is important that program facilitators and instructors are welltrained in inclusive language and able to make new attendees feel

#### Limitations

Generalizability of these results is limited due to the small sample and that eligible participants required internet access and literacy.<sup>25</sup> Online questionnaires are a feasible method of surveying older adults, but they are limited in representing a sample size with internet access.<sup>31</sup> As such, due to the online nature of the survey, our findings may be biased towards tech-friendly solutions. Respondents were mostly Englishspeaking Ontarians (Table 1). Our sample is biased towards those already interested in health-particularly food, nutrition, and exercise. Self-report questionnaires are subject to social desirability bias and respondent interpretation. Furthermore, the predicted duration of our survey, according to Qualtrics Survey Software, was 15.5 minutes; Qualtrics indicates that questionnaires tend to have substantial respondent break-off if they take longer than minutes.<sup>32</sup> Online questionnaires twelve are also accompanied by the potential for misunderstanding. As there is no interviewer to make clarifications, questions may be interpreted differently by respondents. Due to limited research on community-dwelling PWMC, there is a need to recruit representative random samples of older adults in the community-especially from equity-deserving groups-in the future. Finally, our survey was created and conducted prior to the COVID-19 pandemic. Since then, online exercise programming, especially for groups with significant health or functional challenges, has seen ample improvement. Such improvements over the past two years have dramatically accelerated our ability to support persons living with dementia and their CPs in exercise programming online.33 Future researchers must be mindful of the aforementioned limitations and aim to recruit a more diverse sample in relation to technological literacy, geography, etc. Future studies may also wish to investigate how a low-cost program can be established and implemented to support this group.

welcome. These preferred elements should be taken into consideration for future program design and development to improve their feasibility and acceptability.

Ultimately, content and format of community programs to support PWMC, CPs, and CPWD need flexibility and tailoring to individual challenges and preferences.20,21,24 The CPs' role as a supportive partner for CPWD must also be considered in wellness programming.<sup>17,26</sup> In addition to adaptable content, these findings support the need to reduce barriers via flexible delivery (e.g., online). Technology-based tools as a means for educating PWMC and CPs on food, nutrition, and exercise may be of interest for future studies.

#### Strengths

Our online survey was available across Canada in both English and French (telephone and mail options also available), which addressed specific geographical and language barriers. Multipleselect answers provided respondents with the opportunity to choose all applicable answers. There are differences in the experience of living with dementia, and we addressed this by constructing one open-ended questions for respondents to elaborate on their own challenges and preferences surrounding food, nutrition, and exercise.

# CONCLUSION

This study aimed to understand nutrition and exerciserelated challenges and program preferences of PWMC and their CPs to guide wellness program planning. Many PWMC, CPs, and CPWD (reported by their CPs) experienced challenges surrounding food intake, meal preparation, time, and motivation. In terms of exercise, participants seeked to exercise twice or more times per week, though many experienced challenges with weather, mobility, balance, pain, energy, time, and existing health conditions. While most were interested in a community wellness program encompassing nutrition and exercise, specific preferences for activities and delivery modes were diverse; hence, future programs for this demographic require flexibility in both content and delivery.

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### **CONFLICTS OF INTREST**

The authors have no conflicts of interest to declare.

### **OTHER DISCLOSURES**

The authors have nothing to disclose.

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