

Overcoming Recruitment Challenges for Securing a Survey Sample of Caregivers of Community-Dwelling Older Adults with Multiple Chronic Conditions

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Abstract

This paper discusses the challenges in recruiting a diverse sample of caregivers of older adults with multiple chronic conditions in two Canadian provinces – Ontario and Alberta, as well as the successful strategies to overcome these challenges. Four strategies were employed to overcome the recruitment challenges experienced. These included: (1) using a multi-pronged recruitment strategy with persistence; (2) knowing the location of the sample in the community; (3) weekly reporting by team members primarily responsible for recruitment and data collection, and; (4) regular team meetings to build on successful recruitment strategies while troubleshooting new approaches. These four strategies complemented one another. The most effective strategies in Alberta (recruiting over 50% of participants) were newspaper advertisements and working with the Alberta Caregivers Association and the Alzheimer Society of Alberta/NWT. In Ontario, the most effective strategy was door to door flyers (recruiting 61.5% of participants).

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Introduction

Recruitment of participants in field research is generally a challenge, but is particularly challenging when recruiting busy family caregivers who are caring for community-dwelling older adults with multiple chronic conditions (MCC). This is especially so if these family caregivers are also employed in paid work. There is literature on recruitment strategies used with community-dwelling family caregivers, however there are none to date that address the recruitment challenges and strategies to overcome these challenges, with respect to family caregivers of community living older persons with MCC.

The population of older adults with MCC represents one in three community-living older adults in Canada and is predicted to grow substantially given the increased longevity of the Canadian population (1). Family caregivers provide a large proportion of care to these individuals and often experience high levels of caregiver strain. This paper reports on the recruitment challenges and strategies to overcome them in securing a diverse sample of caregivers of older adults with multiple chronic conditions in two Canadian provinces – Ontario and Alberta. MCC was operationalized as a diagnosis of dementia, diabetes and/or stroke in the last 6 months prior to participating in the research, in addition to a minimum of two other chronic conditions. Given the lack of longitudinal evidence in the literature, this study is particularly unique in that it captures the caregiving experience across time, specifically two time points, six months apart. The results are important in that they have the capacity to shape where supports may be needed for these caregivers. We begin the paper with a brief review of published literature on recruitment challenges of community-dwelling caregivers before describing the context of the study. Next we describe the sample recruitment strategies used, the challenges, and the keys to our success in securing and retaining the sample, given the

longitudinal nature of the study. A discussion and conclusions for further research is then provided.

Recruitment Challenges of Community-Dwelling Caregivers

Participant recruitment is a major issue in gerontological research, with challenges causing potential study redesign, delays in starting and consequently completing the study, or resulting in findings that are potentially non-representative or even invalid. Although few studies actually report the recruitment methods used, and the success thereof, there are a growing number of researchers dedicated to reporting these important details. For example, caregiver burden, medical concerns, and indifference have been noted as challenges to participant recruitment (2).

Others have noted mistrust and transportation obstacles (3, 4, 5). UyBico, Pavel, and Gross (6) wrote a systematic review on interventions to improve recruitment, and reported that additional barriers to minority recruitment include a lack of confidentiality, fear of safety, scheduling conflicts, poor access to medical care, lack of knowledge, and language/cultural differences. Finally, excessive restrictions on eligibility, such as extensive inclusivity criteria, may limit the ability to generate an adequate sample size needed for statistical power and representation of the target population (7, 8).

Experimental Procedure

The purpose of this study was to enhance our understanding of the experiences of diverse family caregivers providing care to older adults with multiple chronic conditions (MCC) as we know very little about this particular caregiving population. Our motivation to conduct this research was to inform how to best maintain the health of this targeted caregiver population, in order to uphold their quality of life and sustain their ability to provide care. This two-province

caregivers, including a representation of various ethnicities, ages, geographical locales (i.e., urban, rural), employment status (i.e., full-time, part-time, other), and gender. Those who agreed and met our inclusivity criteria took part in up to 3 one-hour interviews. Inclusion criteria for the study were: a) care recipient diagnosed with dementia, diabetes and/or stroke in the last 6 months prior to participating in the research and having at least two other chronic conditions; b) participant must be actively providing care to an older adult (65 or older) with MCC living in the community; c) participant must be 18 years of age or older, and; d) English speaking. Survey data were collected at two time points, six months apart, to capture the active nature of caregiving for older persons with MCC. A small group of 40 survey participants (20 per province) were invited to participate in a third qualitative stage involving an in-depth semi-structured interview. The subset of participants recruited for this stage was based on an analysis of the survey characteristics shown to impact caregiver burden, and included men, those working full-time, visible minority/ethnic minority, and those residing in rural geographies.

Findings were many and included the significance of caregivers' self-efficacy, or confidence in one's ability to deal with difficult situations, which was found to be an important predictor of caregivers' quality of life, physical and mental health (9). The significant positive relationship between self-efficacy and quality of life/health suggests the need to increase confidence in family caregivers' ability to deal with difficult situations. The findings of the study will be used to design ways to support family caregivers of persons with MCC. This study received ethics approval from the University of Alberta Research Ethics Office and the Research Ethics Board of McMaster University (2013 104).

Data Collection

Initial Time 1 surveys were initiated in July 2013 and final Time 1 surveys were completed in June 2014. Surveys were conducted with participants on the phone, via skype or in-person. A small number of participants (approximately 4-6 in total) completed the survey by hand and returned the survey by mail. A sub-set of participants involved in the qualitative stage were interviewed within two months of the Time 2 survey. The process of informed consent was undertaken with each participant; each participant was given one copy of the

consent form to keep and another was completed and retained by the researchers. Individuals in the study were compensated CND \$25, either in cash or via gift card for each session in which they participated.

During the Time 1 and Time 2 surveys, caregivers were asked to complete the Health-Related Quality of Life tools (SF-12 and McGill Quality of Life), General Self-Efficacy (GSE), 12-item Short-form Zarit Caregiver Burden Interview, the BEM sex roles inventory, a Work Interferences Scale and a survey on frequency and types of formal services accessed (10). Demographic information was also collected during the Time 1 survey.

A sub-set of survey participants were invited to participate in an in-depth semi-structured interview after the second survey. These semi-structured interviews will provide an audio-taped, in-depth understanding of how the experience of caregiving is impacted by the multiple determinants of interest, while also probing the dynamic nature of caregiving for older adults with MCC. Interviews averaged 1 hour in length. All qualitative data were transcribed verbatim, imported into NVivo and analyzed thematically. Given the gendered nature of informal caregiving, men were oversampled.

Results

A total of 194 (107 in Ontario and 87 in Alberta) caregivers of older persons with MCC were recruited to the study and participated in the first survey. A much larger number responded but, once pre-screened, did not meet the inclusivity criteria. Following the development of an appropriate recruitment plan that was responsive to the unique inclusivity criteria of the population was critical to the success of a research study. After first contacting the likely suspects on the service landscape (i.e., disease-specific organizations), and using the typical recruitment techniques, such as posters and invitation fliers, we moved onto more innovative strategies, such as using social media. Participants were recruited to the study through a variety of means. A wide range of organizations both within Alberta and Ontario collaborated and helped with the recruitment of participants, the pre-screened numbers which are found in Tables 1 and 2. In Ontario, the research team contacted not only homecare organizations who provide service for seniors with MCC, but also contacted various research organizations working on

Table 1: Summary of Recruitment Success by Strategy/Organization for Ontario

Number of participants recruited	Recruitment Strategy/Organization
65	Local Newspaper Door-to-Door distributed Flyer
7	Newspaper Ad
7	Participant Referral (snowball method)
5	Saint Elizabeth Home Care
4	Victorian Order of Nurses (VON)
3	Coffee News
3	Parkinson caregiver support group
3	Alzheimer Society
2	Parkinson's Society
2	Research flier at family doctor's office
1	Caregiver support group
1	Kijiji Ad
1	Home Care
1	Senior center research postcard
1	Church caregiver support meeting
1	Flyer and Caregiver Support group
107	TOTAL

Table 2: Summary of Recruitment Success by Strategy/Organization for Alberta

Number of participants recruited	Recruitment Strategy/Organization
22	Alzheimer's Society (various)
20	Alberta Caregivers Association
20	Newspaper Advert
5	Another participant
3	Edmonton Examiner Advert
2	Alberta Beach Seniors 50+ club
1	Coffee News
1	South East Edmonton Seniors Association (1 bulletin board)
1	POSTER-IGA Grocery Store
1	POSTER-Starbucks
1	POSTER-Uni library
1	POSTER-Uni CAPS
1	POSTER-public library
1	POSTER-Eckville Friendship centre
1	POSTER-Church in Irma
1	POSTER-Pharmacy
1	Family Caregiver Centre in Calgary
1	Edmonton Senior Coordinating Council
1	SE Community League
1	Facebook contact
1	Heart & Stroke Foundation
87	TOTAL

seniors' issues, such as McMaster University (Table 1). The most successful recruitment strategy in Ontario was the delivery of door to door recruitment flyers resulting in 61.5% of the participants.

In Alberta, key community organizations and newspaper advertisements were critical to recruitment included the Alzheimer Society and the Alberta Caregiver's Association (Table 2). These three strategies resulted in recruiting 50% of the participants in Alberta.

Challenges & Subsequent Strategies

In addition to sharing the same recruitment issues as with other caregiver studies, as noted in the review above, recruitment for this research study was challenging due to a number of reasons. First, we were recruiting from the community, where caregivers are dispersed amongst every other type of demographic. Unlike caregivers caring for patients in confined and delineated service settings like long-term care facilities or nursing homes, finding community-dwelling caregivers is a form of investigating. Second, we were aiming to capture a select group of caregivers – those of older adults with MCC. MCC was operationalized as diagnosis of dementia, diabetes and/or stroke in the last 6 months prior to participating in the research, in addition to a minimum of two other chronic conditions. Meeting these criteria was challenging when the organizations we were working with often represented clients who were diagnosed only with dementia (i.e., Alzheimer's Society), stroke (Heart & Stroke Foundation) or diabetes (Canadian Diabetes Association). Thirdly, we ideally

wanted a diverse sample of caregivers, representing a range of socio-demographic characteristics, as noted above. This was somewhat captured in the study design, given that we were sampling across two provincial jurisdictions, but due to health care being a provincial responsibility in Canada, each province has a unique health care system and a different service landscape, requiring the research team to map out a unique recruitment strategy for each province. We had particular challenges with finding an ethnically diverse sample, which we never did manage to recruit.

The large number of wide-ranging organizations and strategies used for recruitment across a seven-month period reflects the challenges experienced by the research team in accruing the sample numbers needed. A number of subsequent strategies were employed in achieving the sample size, as will now be discussed. These included: (1) using a multi-pronged recruitment strategy with persistence; (2) knowing the location of the sample in the community; (3) weekly reporting by team members primarily responsible for recruitment and data collection; and (4) regular team meetings to build on successful recruitment strategies while troubleshooting new approaches.

Using a multi-pronged recruitment strategy with persistence.

A multi-pronged recruitment strategy was essential given that the target sample was living in private residential dwellings in the community and hard to reach given their often limited mobility and limited time.

As others have discussed, recruiting through service providers is fraught with confidentiality issues and participant concerns regarding impact on quality and quantity of service provision. In addition to using service providers, we approached a wide range of community organizations to assist with recruitment. Further we asked our affiliated gerontology research centers in each of our corresponding universities to distribute the attached invitation (Figure 1).


how many people received the study information so the response rate was unknown.

Knowing the location of the sample in the community.

Given that the target sample was living in private residential dwellings in the community, those geographical areas that had a relatively large number of residents aged 65 and older were targeted for distribution of study recruitment advertisements in free weekly local community newspapers delivered door-to-door. As

An Invitation to Participate

A Study of Family Caregivers of Older Adults with Multiple Chronic Conditions



Purpose: The purpose of this study is to enhance our understanding of the experiences of family caregivers providing care to older adults with multiple chronic conditions. The goal of this research is to suggest how the health of caregivers can be maintained.

Expectations: To participate in up to 3 one-hour research sessions in your home or an alternative location over the caregiving process. The first two sessions will include asking survey questions. The third session will be a conversational interview.

Please note: The service organization distributing this postcard will not be told who participated or who did not, and your decision to participate in the study will have no effect on any services provided by the organization, or your standing with the organization. There are minimum potential risks involved in this research. The risks associated with participating in the study are no greater than risks you would encounter in everyday life. There is a possibility that the data collection process may cause some psychological upset given the nature of the questions asked. In order to mitigate this, the researcher has been trained in a range of caregiver-related issues. In addition, the researcher will have access to a list of resources, such as those available in the community; this will allow the researcher to connect you to the resources that you seek or wish to explore further.

In addition to the traditional distribution of posters in targeted locales, we purchased ads in free advertising fliers, such as 'Coffee News', found in local coffee franchises. We also printed thousands of invitations for inclusion in free weekly local community newspapers delivered door-to-door (see next section). In addition to word-of-mouth, on-line social media was also used, in addition to Kijiji. One of the challenges with using a multi-pronged recruitment strategy is we did not know

determined by Statistics Canada (11) community profiles from 2011, together with first-hand experience of the demographic characteristics of the regions concerned, we delineated the census tracts characterized as having a relatively large proportion of elderly aged 65 years or older. We then worked with the overwhelmed with caregiving, person they were caring for was admitted to long term care or died, unable to be reached). This retention rate was higher than expected as the second

advertising agent associated with the local free newspapers distributed door to door each week, to have a research recruitment advertisement insert added to the newspaper. The newspaper advertising agent associated with the specified free local papers confirmed our research, with respect to the census tracts with a large aging demographic in the specified geographies. Once we overlaid the census tracts with the newspaper distribution catchment, we were able to delineate the communities receiving the flier. Although used in both provinces, this strategy was more successful in Ontario.

Weekly reporting by team members primarily responsible for recruitment and data collection.

The research trainees were the team members primarily responsible for the leg work involved in recruitment. There was one trainee per province. Each was asked to keep track of their sample numbers by organization/recruitment strategy and provide a weekly report back to the larger research team. This expectation kept the research trainees conscientious about keeping on top of recruitment, being sure to note which strategies/organizations were experiencing success, and following through with new strategies. It also provided a way for the whole team to track recruitment and monitor patterns in participant numbers. Further, the weekly report provided a way to have the two research trainees communicate and exchange with one another, which they did specific to recruitment, data collection and follow-up.

Regular team meetings to build on successful recruitment strategies while troubleshooting new approaches.

The research team met on a regular basis, averaging once monthly. In addition to determining how we could build on successful recruitment strategies, such as the targeted distribution of recruitment fliers by geographical areas that had a high proportion of seniors, the senior researchers on the team were able to share their expertise on new strategies to use, such as placing an ad in the free news circular 'Coffee News' offered at a popular coffee franchise. Further, the seasoned senior researchers shared their networks of service organizations and the relevant contacts for these organizations. Rather than set goals or targets by specific dates, the team decided to work intensively in realizing a multi-pronged recruitment strategy. This allowed us to meet our

sample size.

Sample Retention

The study retention rate was 95.4 % as 9 (4.6%) participants did not participate in the second data collection for a variety of reasons (e.g. likethemselves. In addition, they also remarked that it was helpful to them to talk with the non-judgmental research assistants. They were someone who listened to them, when other people did not. It is also possible that being involved in the research provided lonely and isolated participants a positive social opportunity.

Discussion and Conclusions

Even though we were unable to reach our goal of 200 participants, we met the sample needed to achieve statistical power in our analysis. We were unsuccessful in meeting the minority/ethnic diversity we wanted and would need to plan this more carefully in the future (2, 6). Successful strategies seemed to vary from province to province. In Alberta the most successful strategies were those in which the Alberta Caregiver Association and the Alzheimer Society assisted with recruitment. In contrast, the local door-to-door flier in geographically targeted areas known to have a high seniors' population was more successful in Ontario. strategies were employed to overcome the recruitment challenges experienced. These included: (1) using a multi-pronged recruitment strategy with persistence; (2) knowing the location of the sample in the community; (3) weekly reporting by team members primarily responsible for recruitment and data collection, and; (4) regular team meetings to build on successful recruitment strategies while troubleshooting new approaches. These four strategies complemented one another and worked in unison to meet the recruitment target.

data collection was at 6 months. One of the likely reasons for the high retention rate when collecting data via the interview survey was due to the researchers providing an open conversational format so that participants often felt free to share their experiences beyond the survey when necessary. This contributed to the comfort level of participants, built trust in the researcher-participant relationship, and helped with retention as participants were therefore more interested to do the follow-up survey.

Data collected as part of our notes from our monthly meetings regarding retention suggested that many of the participants continued with the study for altruistic reasons. The participants often remarked that they were participating in the study to help others

Four
Recognizing the need to recruit a sufficient and representative sample in order to ensure statistical power and the generalizability of study findings, a number of suggestions for recruiting this population are now provided. Given that a multipronged approach is needed to reach community-dwelling caregivers, it is important to secure adequate funding for these strategies, which need to be reflected in the project budgets. It would be important in future research with this population to plan for a longer recruitment period, and to incorporate the use of social media in the recruitment strategy (12) particularly if a truly diverse sample was sought. The challenge of recruiting an ethnically diverse sample requires a dedicated person with the trusted networks.

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Ethics

This study received ethics approval from the University of Alberta Research Ethics Office and the Research Ethics Board of M

Declaration of Conflicting Interests

The authors declare that they have no conflict of interest.

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