

Improving the Cooperation Rate of Older Adults and Their Caregivers in Research Surveys

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Key Words

Recruitment · Initial contact · Advanced letter · Caregiver · Frailty · Older people

Abstract

Background: Recruiting older adults, their family members and their home care workers as participants in research studies is particularly complicated. This might be due to medical or cognitive problems of the older adult as well as the high workload and shortage of time experienced by caregivers. The present study compared the contribution of two different versions of an advanced letter followed by two different versions of a recruitment phone call to the cooperation rate of older adults, family caregivers and home care workers in a face-to-face survey. **Methods:** A quasi-experimental design was used to compare the contribution of the different types of appeal. A total of 2,014 caregiving units (composed of an older adult, a family member and a home care worker) were randomly sampled from a list of Israeli long-term care insurance beneficiaries. 74.32% of the sampled caregiving units were eligible to participate in the study. The first group of participants received formal and succinctly phrased written and oral appeals – an advanced letter followed by a recruitment phone call. The second group of participants received the original formal and succinctly phrased advanced letter, but a revised recruitment phone call that included a more

personal approach, the provision of broader information about the study and the avoidance of words with a possible negative connotation. The third group of participants received both a revised advanced letter and a revised recruitment phone call. **Results:** Using the succinctly phrased written and oral appeals, we had a cooperation rate of about 50% for the entire caregiving unit. Using a revised advanced letter and a revised recruitment phone call yielded an increase of 20–25% in the cooperation rate for the entire caregiving unit. Using the revised recruitment phone call and the original advanced letter yielded an increase in the cooperation rate only among migrant home care workers. **Conclusion:** This study showed that by changing the format of appeal we can increase the cooperation rate of older adults and their caregivers in a research survey. This study also pointed out the importance of the advanced letter.

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Introduction

Surveys are an effective and productive research method that allows the examination of a variety of topics at a relatively low cost and over a short period of time [1]. For a survey to accurately represent the target population, it must not only be based on a representative sample but also have the highest possible participation rate. In other

words, the external validity of survey findings depends, among other things, on the actual participation rate among the surveyed population [2].

Recruiting older adults and their family members as participants in research surveys is particularly complicated for a number of reasons. Among these are the medical or cognitive conditions of older adults, which often prevent them from participating in studies [3, 4], views of older adults concerning research studies in general [5], and the characteristics of the research design (e.g. the amount of time required from the participant and data collection procedures [6]). For example, older adults with a hearing loss may have difficulties completing the questionnaire or following the interviewer's instructions, and therefore might be more likely to refuse participation in the study [7]. Individuals with vision impairment might have difficulty completing a mailed questionnaire, and older adults who are socially isolated might find it difficult to confide in a researcher [3]. Another main issue regarding recruitment of older adults concerns their cognitive state and informed consent regulations. Cognitively impaired older adults present with a wide range of functional levels [8]. Determining their level of competency to participate in a research study could be very challenging, as it depends not only on their mental capacity but also on the particular research design [9]. For instance, some older adults who suffer from cognitive impairments might not be able to participate at all or have to be interviewed indirectly, with the mediation of a family member [3]. It seems that frail older adults, who suffer from substantial functional impairments and poor health, are more difficult to recruit into research studies [10]. Their participation might also be subject to their family members' approval, as family members tend to serve as official or unofficial guardians [11]. Hence, under certain circumstances, the will of family members might override that of the older adult [12].

The inherent complexity of recruiting older adults in general, and the fact that some of them are deemed ineligible for interviews, sometimes leads researchers to interview family members – a spouse or children – assuming that they are able to provide an adequate first-hand estimation of the physical, cognitive and emotional conditions of the older adult. However, recruiting family members might prove as difficult as recruiting the older adults themselves. Many family members serve as caregivers, and often have to divide their time and mental resources between caring for their children and caring for their parents [13], in what is known as 'multigenerational caregiving' [14]. It seems that even when a paid care worker is

employed in order to assist the older adult, family members continue to actively support the older adult [15]. In their exhausted and worn-up state [16], they are frequently less inclined to participate in studies [5]. Despite the growth in research on family caregivers over the last decade, the recruitment of family caregivers continues to be a difficult task [13]. The fact that many of the studies on family caregivers are based on nonrepresentative samples highlights the obstacles inherited in recruiting this population [17].

Given the fact that informal care provided by family and friends is often supported by formal (paid) sources of care, such as home care [18], another option for gaining information about older adults is through paid home care workers. These workers assist older adults with activities of daily living (ADL) and instrumental ADL. Nonetheless, similar barriers to those associated with the recruitment of family members also seem to exist in the case of home care workers. Specifically, live-in (i.e. round-the-clock) home care workers have limited opportunities to participate in research studies due to the intensive level of care they provide to older adults. In addition, in many countries, live-in home care workers tend to be migrants [19], who lack the local language skills [20] and have lower interest in providing information about themselves, given their unsecured status in the country [21].

The Importance of the Initial Appeal

Researchers use various techniques and methods to recruit participants, with the aim of engaging potential participants as rapidly as possible. People who have to be persuaded to participate in a research study may provide different replies from those who had agreed to participate in the first place [22]. Moreover, repeated persuasions may clash with the principle of informed consent [23].

A commonly used method is an advanced letter, explaining the purpose and the type of the research, and the cause and organization for which it is being conducted [24]. A formal advanced letter of appeal is thought to reduce resistance to research participation because it is less invasive than a direct approach such as a phone call. Researchers who have studied the effects of an advanced letter on older adults concluded that a letter tends to make a very positive contribution [25]. For older adults, two elements seem to be particularly important: (a) there seems to be a preference for a short and concise letter over a long one [26] and (b) the information provided about the research should be phrased clearly [11]. In face-to-face surveys, an advanced letter is usually followed up by a phone call in order to schedule a time and place for the survey interview.

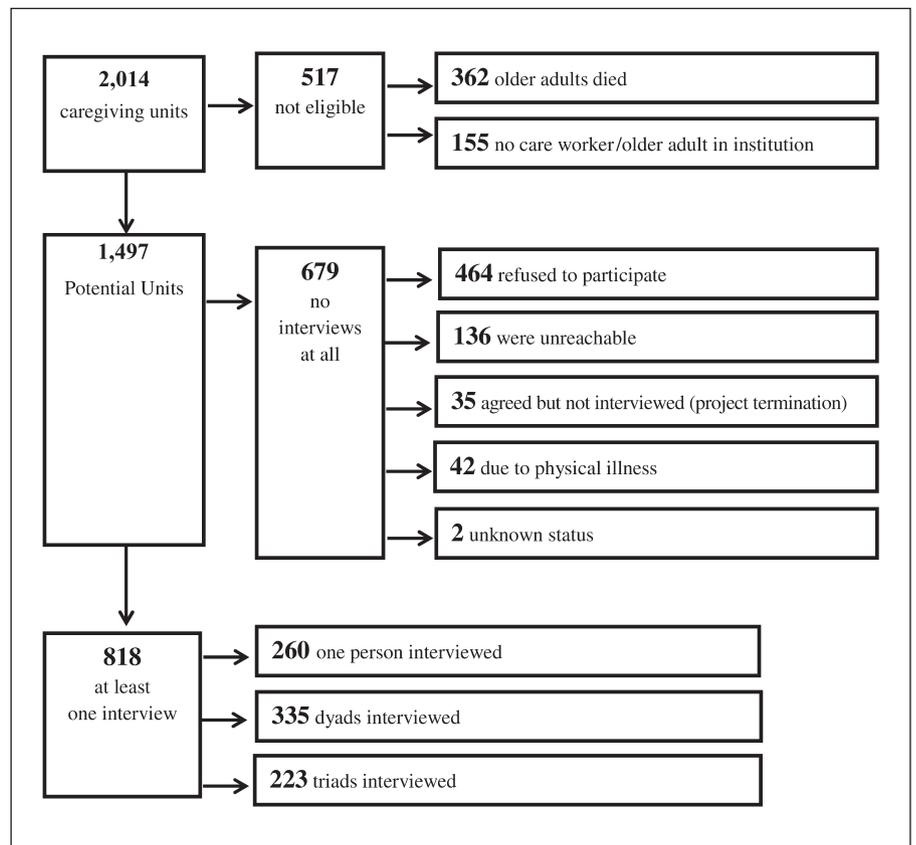


Fig. 1. Sample flow.

The Present Study

Given the numerous challenges associated with the recruitment of older adults and their caregivers into research studies, the present study examined the contribution of two different versions of an advanced letter followed by two different versions of a recruitment phone call to the cooperation rate of older adults, family caregivers and home care workers in a face-to-face survey. We chose to compare the cooperation rate, defined as the number of participants that were actually interviewed, divided by the number of eligible candidates who were reachable [27], and not the ‘response rate’, as the response rate includes in the denominator also participants that are not reachable [28]. As such, the response rate is irrelevant to examining the varied contribution of personal appeals.

We hypothesized a difference in cooperation rate among the three types of advanced letters and recruitment phone calls. We expected that a less formal and more personal approach that provides broader information about the study would increase the cooperation rate in the study.

Methods

The Sampling Process

In this study, we aimed to recruit 500 ‘caregiving units’. A caregiving unit was defined as a triad comprised of (a) an older adult, (b) a family member who is the primary caregiver and (c) a home care worker, who could be either a live-out Israeli or a live-in migrant.

Because we expected the interview process to take over a year, we adopted the ‘wave sampling’ method of Sharkey and Haines [29], who, like us, interviewed community-dwelling older adults. Following this sampling method, a relatively small number of potential respondents (‘wave’) is sampled each time, and a new wave is approached only when the previous wave is close to exhaustion. When compared to sampling the entire sample at once, ‘wave sampling’ shortens the time that passes between the delivery of an advanced letter and the actual interview.

After the study had been approved by the ethics committee of Bar Ilan University, and by the National Insurance Institute of Israel (NIII), a random stratified sample of older adults over the age of 70 who live in the center of Israel was drawn from the pool of older adults who receive financial assistance from the NIII under the long-term care community law (fig. 1). Stratification was based on age (70–74, 75–85, 85 and above), gender and socioeconomic geographical area (affluent, middle class, poor) of the older adult. The sampling frame consisted of 15,564 older adults who were the

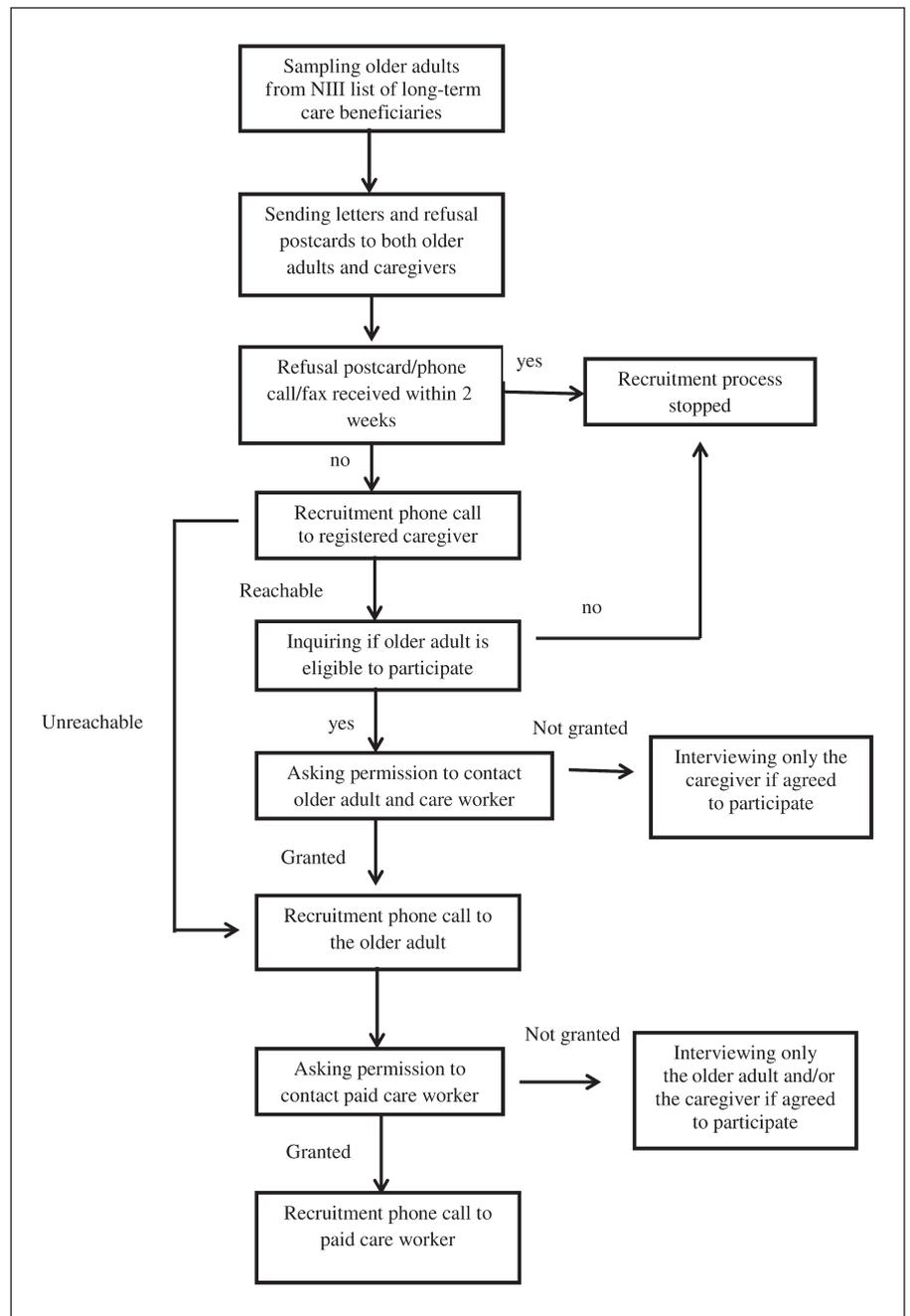


Fig. 2. Recruitment process.

recipients of the Israeli long-term care insurance and lived in the center of Israel in January 2011.

The initial criteria for the inclusion of a caregiving unit were based on the characteristics of the older adult. Older adults had to: (a) live in the center of Israel and (b) be legally entitled to employ a live-in migrant home care worker for health reasons (as only the most functionally impaired older adults are entitled to have a live-in migrant home care worker) and (c) be over the age of 70. Individuals below that age who are entitled to a live-in migrant home care worker are usually characterized by severe impairments which

occurred at an earlier age. Thus, they do not represent the majority of older adults who rely on home care services.

After eligibility had been established, specific inclusion and exclusion criteria were implemented. We interviewed only Hebrew- or Russian-speaking older adults. Family members were interviewed if they had records in the NIII or were identified by the care recipients as the primary caregivers. They also were either Hebrew- or Russian-speaking. Israeli home care workers were interviewed only if they were Hebrew-speaking. Migrant home care workers were interviewed only if they were English- or Russian-

speaking. Despite our interest in the triad, we interviewed even if only one member from each caregiving unit was available for an interview.

We conducted 5 sampling waves and sampled 2,014 caregiving units. Of the overall pool, 517 caregiving units were found to be ineligible and excluded from the study. Hence, the number of potential caregiving units was 1,497 – 74% of all caregiving units contacted. Of these, in 818 units at least 1 member was (see fig. 1 for details).

The Recruitment Process

Recruitment was carried out in two stages (fig. 2): the first stage consisted of mailing an advanced letter to the older adult and his or her primary family caregiver. No letters were sent to home care workers because they are not registered with the NIII. The second stage started 2 weeks after the advanced letters had been sent. A recruitment phone call was placed to those who did not refuse further contact. We deliberately attempted contacting the family member prior to contacting the older adult, in order to acquire information regarding the cognitive and physical status of the older adult and to gain the confidence of the older adult through the preliminary cooperation of his or her family member. This was especially important when contacting older adults whose cognitive state was questionable according to the tests made by the NIII prior to this study.

The original advanced letter (see the Appendix) began with greetings, addressing the candidate by his/her full name. A very short explanation about the study and the collaborating parties involved in the study was provided. It was also noted that there was no obligation to participate, that confidentiality would be maintained and that the analysis would be performed anonymously. The letter was signed by the research officials, who provided their contact information.

The original recruitment phone call began with a brief presentation of the interviewer who provided his or her name and affiliation. The researcher mentioned the advanced letter that was sent prior to the phone call. The overall purpose of the study was described as improving the quality of lives of older adults, family members and home care workers. If interested, the interviewer scheduled a face-to-face interview with the potential participant. As in the original advanced letter, the interviewer emphasized that (a) there was no obligation to participate in the study, (b) analyses would be performed anonymously and (c) confidentiality would be maintained.

Revisions of the Advanced Letter and the Recruitment Phone Call

The first wave of recruitment yielded a cooperation rate of about 50% for the entire caregiving unit. Although this rate is acceptable in survey research involving older adults, we aimed to obtain a higher cooperation rate in order to increase the representativeness of our sample and to allow all 3 members of the caregiving unit to participate in this study. As a result, we revised the style of the recruitment phone call during the second wave. In the third wave and beyond, we also changed the format of the advanced letter.

The following main revisions were made in subsequent appeals:

Use of a Personal Approach

Whereas the original appeals were formal ('you were sampled as an eligible participant') and were phrased succinctly, the revised

appeals emphasized both egoistic and altruistic motives for participation (e.g., 'it is very important for us to understand the preferences of care recipients and their family members'). In addition, we emphasized the subjective aspects of the research, using expressions such as 'your opinion' or 'your point of view'.

The Provision of Broad Information about the Study

Whereas the original appeals described the purpose of the study in a single succinct sentence ('the topic of the survey is home care services for long-term care insurance beneficiaries'), the revised appeals provided broader information about the study and its aims, as well as explanations about the type of research questions the participants might be expected to answer (e.g. 'among other things, you will be asked about your preferences regarding home care and your relationship with your home care worker').

The Avoidance of Words with a Possible Negative Connotation

The literature suggests that certain people, especially older adults, tend to ascribe a somewhat negative connotation to the word 'research' [30]. We therefore replaced this word with the term 'an interviewing project' in the beginning of the appeal. Nevertheless, right after this preface, the goals and purpose of the study were clearly articulated to participants, and we remained explicit about our intentions to aggregate and analyze the data for research purposes. The fact that interviews were conducted as part of a research study was also written in the informed consent form.

Study Design

These changes made to the advanced letter and the recruitment phone call resulted in 3 groups of participants, which were subsequently compared using a quasi-experimental design:

- (1) the first group – 'original style' (n = 384; wave 1) – was comprised of caregiving units that received the original versions of the advanced letter and the recruitment phone call;
- (2) The second group – 'partial revision' (n = 332; wave 2) – was comprised of caregiving units that received the original version of the advanced letter but a revised recruitment phone call.
- (3) The third group – 'full revision' (n = 731; waves 3–5) – was comprised of caregiving units that received the new versions of both the advanced letter and the recruitment phone call.

Analysis

Pretest Analysis

Preliminary analyses were conducted in order to confirm that all 5 sampling waves were drawn from a single pool of potential participants and to identify potential differences between those who agreed to participate in the study and those who did not. Older adults were compared on several characteristics, including age and gender, and 3 indicators, used to determine the older adults' eligibility for home care services by the NIII (table 1). These indicators are (a) 'ADL score', which represents the extent of physical dependency of the older adult; the score ranges between 0 and 9.5, with a higher score indicating greater dependency in ADL; (b) 'living status score', which indicates whether the older adult lives alone or not (older adults who live alone are given 2 points, and those who live with a family member receive 0 points); (c) 'supervision score', which rates the extent of supervi-

Table 1. Comparisons of the characteristics of older adults across the 5 waves of sampling (n = 1,497)

	No revision			Partial revision	Full revision	χ^2/F
	1st wave (n = 384)	2nd wave (n = 332)	3rd wave (n = 331)	4th wave (n = 330)	5th wave (n = 120)	
Male/female, %	28/72	29/71	82/72	31/69	30/70	2.91
Age, years (70–110)	83.93±6.76	83.99±6.24	83.77±6.20	83.73±6.44	84.23±6.83	0.32
ADL score (4.5–9)	5.38±1.59	5.44±1.66	5.13±1.74	5.34±1.59	5.24±1.51	2.72*
Supervision score (0–9)	3.53±4.37	3.58±4.39	3.50±4.37	3.38±4.45	3.43±4.36	0.96

Means ± SD are reported for continuous variables. Frequency is reported for categorical variables. One-way analyses of variance were conducted for continuous variables. χ^2 analyses were conducted for categorical variables. * p < 0.05.

Table 2. Differences in cooperation rates of older adults (n = 725), family members (n = 1,110), migrant care workers (n = 460) and Israeli care workers (n = 315) across the different recruitment methods

	Older adults	Family members	Care workers	
			Migrant	Israeli
Cooperation rates, %				
No revision (a)	39.3	49.1	55.5	46.2
Partial revision (b)	49.7	59.4	77.1	56.3
Full revision (c)	64.6	70.3	78.6	70.8
Differences between recruitment methods				
a versus b				
χ^2	4.30	6.02	11.45**	1.8
OR	1.52	1.51	2.70	1.50
95% CI	1.02–2.28	1.08–2.11	1.51–4.84	0.84–2.71
b versus c				
χ^2	11.04**	9.83**	0.87	4.91**
OR	1.84	1.62	1.08	1.88
95% CI	1.28–2.64	1.20–2.19	0.63–1.88	1.07–3.30
a versus c				
χ^2	32.32***	36.54***	20.17***	13.96***
OR	2.84	2.45	2.93	2.82
95% CI	1.96–4.03	1.83–3.30	1.82–4.73	1.63–4.92
Overall effect χ^2	33.77***	37.29***	22.32***	14.37***

OR = Odds ratio; CI = confidence interval. ** p < 0.004; *** p < 0.001.

sion needed due to the cognitive state of the older adult; it ranges between 0 and 9, with a higher score indicating greater cognitive impairment; the highest score is given to those who suffer from severe dementia and require constant supervision. For the preliminary analyses, χ^2 and t tests and 1-way ANOVAs were performed.

A Comparison of Cooperation Rates

To test our hypotheses and find whether the revisions of the advanced letter and recruitment phone call improved the cooperation rate, χ^2 analyses were performed. All statistical analyses were performed with the IBM Statistical Package for the Social Sciences version 21 [31].

Results

Overall, 2,610 individuals (725 older adults, 1,110 family members, 460 migrant care workers and 315 Israeli care workers) from 1,497 eligible caregiving units were contacted (table 2).

Pretest Analysis

Table 1 demonstrates that there were no differences across the 5 waves of sampling, other than an overall effect on the ADL score. However, a post hoc Scheffé test found no significant differences in ADL across the 5

waves. Among older adults who agreed to participate, there were more men (31.6 %) than women among those who did not agree to participate (22.6%; $\chi^2 = 7.33$, $p < 0.001$). Consistently, the percentage of family members who were the relatives of an older man was higher among those who agreed to participate (33.2 %) than among those who did not agree to participate (24.7%; $\chi^2 = 9.06$, $p < 0.001$). The NIII has no preliminary systematic data concerning the characteristics of family members and home care workers. Hence, their characteristics were not compared across the various waves.

A Comparison of Cooperation Rates

We compared the cooperation rates across the three different recruitment methods. Main effects were found across all types of members in the caregiving unit (older adult, family member, Israeli home care worker and migrant home care worker; table 2). Subsequent χ^2 analyses were conducted to test the following differences:

- (1) 'original style' versus 'partial revision': an original advanced letter and an original recruitment phone call versus an original advanced letter and a revised recruitment phone call;
- (2) 'partial revision' versus 'full revision': an original advanced letter and a revised recruitment phone call versus a revised advanced letter and a revised recruitment phone call;
- (3) 'original style' versus 'full revision': an original advanced letter and an original recruitment phone call versus a revised advanced letter and a revised recruitment phone call.

In total, 12 different χ^2 tests were conducted – 3 styles of appeal (e.g. type of advanced letter and recruitment phone call) multiplied by 4 types of members in the caregiving unit (older adult, family member, Israeli home care worker, migrant home care worker). The cooperation rate as a function of style of appeal is summarized in table 2. Based on the Bonferroni correction, the critical α for determining the level of significance was determined as

$$\alpha' = \frac{\alpha}{k} = \frac{0.05}{12} = 0.004.$$

'Original Style' versus 'Partial Revision'

There were no significant differences in the cooperation rate of older adults, family members and Israeli home care workers who received the 'original style' versus those who received the 'partial revision'. The cooperation rate of migrant home care workers who received a revised re-

ruitment phone call was significantly higher (77.1%) compared with migrant home care workers who received the original version of the recruitment phone call [55.5% ; $\chi^2(1) = 11.45$, $p < 0.004$].

'Partial Revision' versus 'Full Revision'

The cooperation rates of older adults (64.6%), family members (70.3%) and Israeli home care workers (70.8%) who received a revised version of both the advanced letter and the recruitment phone call ('full revision') were significantly higher [$\chi^2(1) = 11.04$, $p < 0.004$; $\chi^2(1) = 9.83$, $p < 0.004$; $\chi^2(1) = 4.91$, $p < 0.004$, respectively], compared with those who received the original advanced letter and a revised recruitment phone call ('partial revision'; 49.7, 59.4 and 56.8%, respectively). No significant differences were found for migrant home care workers.

'Original Style' versus 'Full Revision'

χ^2 tests revealed that the cooperation rate of all 4 stakeholders who received the 'full revision' was significantly higher [64.6% for older adults, $\chi^2(1) = 32.32$, $p < 0.001$; 70.3% for family members, $\chi^2(1) = 36.54$, $p < 0.001$; 78.6% for migrant home care workers, $\chi^2(1) = 20.17$, $p < 0.001$; 70.8% for Israeli home care workers, $\chi^2(1) = 13.96$, $p < 0.001$] compared with those who received the 'original style' (39.3, 49.1, 55.5 and 46.2%, respectively).

Discussion

The present study examined the contribution of two different versions of an advanced letter followed by two different versions of a recruitment phone call to the cooperation rate of older adults, family caregivers and home care workers in a face-to-face survey. A comparison between the cooperation rates following the original appeals versus the revised appeals revealed that the latter increased the cooperation rate by 25.3% for older adults, 21.2% for family members, 24.6% for Israeli home care workers and 23.1% for migrant home care workers.

Further examination of the effect of the various appeals revealed a more complex picture. For older adults, their family members, and their Israeli home care workers, the mere change of wording in the recruitment phone call yielded no significant contribution. However, changing the wording of both the advanced letter and the recruitment phone call resulted in a significant increase in the cooperation rate. This could possibly indicate that the advanced letter – the first encounter with the study – is particularly significant for older adults and their family

members. By the time the phone call was placed, potential participants might have already formed an opinion about the study based on the advanced letter. Thus, the revised recruitment phone call had a lesser effect.

The literature supports our conclusion. Numerous researchers have argued that the advanced letter is crucial to recruiting participants for research studies [24, 25]. For older adults, a preliminary contact in the form of a written document is particularly important. It has been suggested that some older adults may tend to value printed materials, and appreciate the time and thought put into them [32]. An advanced letter may also be a better way to approach older adults because they often take longer to decide whether or not they agree to participate in the study [33].

The situation was different with regard to the recruitment of Israeli home care workers and migrant home care workers, who did not get a personal advanced letter. Changes made to the recruitment phone call improved the cooperation rate of migrant home care workers but not that of Israeli home care workers. A possible reason for this could be that the Israeli home care workers had read the original version of the advanced letter sent to the older adult as part of their job, whereas the migrant home care workers did not have access to the letter due to language barriers. It is also possible that migrant home care workers had a greater interest in participating in the study because of their heightened vulnerability to abuse and violence [34]. As such, they might have viewed the study as an opportunity to improve their working conditions, which at times tend to be inappropriate [34]. Whereas the original phone call might have awakened suspicion because it was made by a total stranger [35], the revised wording of the phone call might have convinced the migrant home care worker of the good intentions of the interviewer. This might have made it harder for them to refuse participation in the survey, given the norm of obedience to authority that is dominant in many of the non-Western cultures from which migrant home care workers come [36]. Notably, the participation of home care workers in the survey was inherently contingent upon the participation of the older adult and his or her family members. This was indicated by the fact that, out of the 522 caregiving units (that had a migrant home care worker) interviewed, only in 30 units was the home care worker the sole participant.

Despite its contribution, the present study has several limitations that should be taken into account. Some of the improvements in cooperation rate identified could be attributed to the experience gained by the researchers and

the research assistants over time (e.g. their level of confidence when approaching the respondents, their tone of voice, etc.) rather than to a particular recruitment method. Nevertheless, the research assistants were explicitly instructed to follow the written version of appeal that was given to them (and that was revised during the recruitment process as described above). It is also possible that the Bonferroni correction made in order to account for multiple comparisons resulted in inflated type II errors. For example, a significance level of 0.05 would have resulted in significant cooperation rate differences between family members of the 'original style' group and the 'partial revision' group. Another important point is that there was no control group that received a revised advanced letter but not a revised phone call. It was, therefore, impossible to identify the unique contribution of the advanced letter alone. Nevertheless, the study offers an opportunity to evaluate the contribution of various recruitment methods to the cooperation rate of older adults, their family members and their home care workers. Not less important is the external validity of the study, achieved by our representative sample of frail older adults, family members and home care workers. Future research will have to explore whether the recruitment method presented in this study is also beneficial for the recruitment of participants into clinical trials. In addition, the unique contribution of the advanced letter has to be further examined.

Conclusions

To improve the cooperation rate of older adults and their caregivers with research surveys, the use of an elaborated advanced letter and a sufficient recruitment phone call strategy is strongly recommended. Because a substantial portion of the research budget is often dedicated to the recruitment process, learning from our recruitment methods can reduce these costs. The use of an adequately tailored advanced letter and a recruitment phone call can shorten the amount of time dedicated to the recruitment process and increase the representativeness of the recruited sample. In our quest to recruit vulnerable and hard to reach populations such as frail older adults and their caregivers, increasing their cooperation rate means that more voices are being heard. Adequately representing participants' attitudes, thoughts and wishes will better contribute to implementing programs and developing policies that accurately reflect older adults' and their caregivers' needs.

Appendix: Original Advanced Letter

To
Mr./Mrs. _____

(Full address)

The National Insurance Institute in collaboration with the Bar Ilan University has initiated a research survey on home care services provided to older adults. You were randomly chosen as a potential participant in the survey.

For the survey, interviews will be held with you, your primary family caregiver and your home care worker.

A representative of the National Insurance Institute will contact you shortly in order to set up the time for the interviews.

The survey results will be exclusively used for research purposes. We will keep your response confidential and analyze the data anonymously. You are under no obligation to participate in the survey at any stage.

If you do not wish to participate in the survey, please note this in the form attached to this letter. You may return the form to us by post, using the enclosed stamped envelope, or by fax, at (fax number).

For further information, please contact the study PI (phone number)

Thank you in advance for your cooperation.

Sincerely,
Director of Surveys
National Insurance Institute

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