Archives of Gerontology and Geriatrics 59 (2014) 18–24

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger

Review

Challenges and strategies pertaining to recruitment and retention of frail elderly in research studies: A systematic review

Véronique Provencher [a,b,*], W. Ben Mortenson [c], Laurence Tanguay-Garneau [b], Karine Bélanger [b], Marion Dagenais [d]

[a] Université Laval, Department of Rehabilitation, Quebec City, QC, Canada
[b] CHU de Québec/Centre d'excellence sur le vieillissement de Québec, Quebec City, QC, Canada
[c] University of British Columbia, Department of Occupational Science and Occupational Therapy, Vancouver, BC, Canada
[d] Université de Montréal, School of Rehabilitation, Montreal, QC, Canada

ARTICLE INFO

Article history:
Received 19 August 2013
Received in revised form 17 March 2014
Accepted 20 March 2014
Available online 30 March 2014

Keywords:
Frail older adults
Refusal to participate
Patient dropouts
Review

ABSTRACT

Introduction: Recruitment and retention of frail elderly in research studies can be difficult.
Objective: To identify challenges and strategies pertaining to recruitment and retention of frail elderly in research studies.
Methods: A systematic review was conducted. Four databases (MEDLINE, CINAHL, AgeLine, Embase) were searched from January 1992 to December 2012. Empirical studies were included if they explored barriers to or strategies for recruitment or retention of adults aged 60-plus who were identified as frail, vulnerable or housebound. Two researchers independently determined the eligibility of each abstract reviewed and assessed the level of evidence presented. Data concerning challenges encountered (type and impact) and strategies used (type and impact) were abstracted.
Results: Of 916 articles identified in the searches, 15 met the inclusion criteria. The level of evidence of the studies retained varied from poor to good. Lack of perceived benefit, distrust of research staff, poor health and mobility problems were identified as common challenges. The most frequently reported strategies used were to establish a partnership with staff that participants knew and trusted, and be flexible about the time and place of the study. However, few studies performed analyses to compare the impact of specific challenges and strategies on refusal or drop-out rates.
Conclusions: This review highlights the need to improve knowledge about the impact of barriers and strategies on recruitment and retention of frail older adults. This knowledge will help to develop innovative and cost-effective ways to increase and maintain participation, which may improve the generalizability of research findings to this population.

Contents

* Corresponding author at: Université Laval, Pavillon Ferdinand-Vandry, 1050 avenue de la Médecine, Québec, QC, Canada G1V 0A6. Tel.: +1 418 656 2131x8516; fax: +1 418 656 5476.
E-mail address: Veronique.Provencher@fmed.ulaval.ca (V. Provencher).

http://dx.doi.org/10.1016/j.archger.2014.03.006
0167-4943/

1. Introduction

The term "frail older adults" refers to a population with reduced reserves and resistance to stressors, and thus at increased risk of falls, disability, hospitalization and institutionalization (Fried et al., 2001). Based on recent studies, they represent 7–23% of community-dwelling older adults (Song, Mitnitski, & Rockwood, 2010; Syddall et al., 2010) and this proportion is likely to increase as the population ages (Collard, Boter, Schoevers, & Oude Voshaar, 2012). Frail elders account for a large proportion of patients enrolled in rehabilitation programs (Wells, Seabrook, Stolee, Borrie, & Knoefel, 2003) and are major consumers of home care services (Rochat et al., 2010). Despite their growing numbers, little is known about the complex needs of this population (Rockwood & Mitnitski, 2011). This lack of knowledge could lead to providing inappropriate health care services to vulnerable older people (Bergman et al., 2007).

Although more research is needed with this population, recruitment and retention of frail elderly in research studies represents a challenge. Some studies have reported lower rates of enrollment and higher drop-out rates in this group (Chatfield, Brayne, & Matthews, 2005; Harris & Dyson, 2001), especially in longitudinal studies on health and function (Kempen & van Sonderen, 2002). This could lead to misrepresentation of frail older adults in research studies and, ultimately, to erroneous conclusions about the effects of interventions on them (Barry, 2005). On one hand, since frail older adults are at a higher risk of adverse outcomes, interventions may not be as effective for them and may even produce worse side effects (Bergman et al., 2007; Ferrucci et al., 2003). For example, due to their vulnerability, frail older adults may have more difficulty coping with the consequences of surgery following a hip fracture than non-frail older adults (Menzies, Mendelson, Kates, & Friedman, 2012). More specifically, in this population, prolonged hospitalization is more likely to lead to deconditioning (Dasgupta, Rolfson, Stolee, Borrie, & Speechley, 2009) and anesthesia is more likely to trigger cognitive impairments (delirium) (Leung, Tsai, & Sands, 2011). On the other hand, since even minor changes may have a huge impact on their functional outcomes, small improvements may be clinically significant (Gitlin, Winter, Dennis, & Hauck, 2008; Lally & Crome, 2007). For example, it is expected that some interventions (e.g., nutrition or exercise programs, extended rehabilitation, and environmental home modifications tailed to their specific needs) may lead to modest improvements of their function or autonomy (Kelaiditi, Van Kan & Cesari, 2014; Theou et al., 2011; Wells et al., 2003), which can be sufficient to enable them remain at home (Mann, Ottenbacher, Fraas, Tomita, & Granger, 1999; Ryburn, Wells, & Foreman, 2009). It is thus important to know how to adapt existing interventions to minimize complications and to measure the real impact of preventative disability programs in this population. However, such knowledge cannot be generalized to older frail individuals unless this subpopulation is included in these studies.

In research with older adults, frailty may contribute to increased rates of refusal or drop-out (Kempen & van Sonderen, 2002). However, little is known about the barriers to participation that pertain specifically to this subpopulation. Since frailty is a complex multidimensional condition (Gobbens, van Assen, Luijkx, Wijnen-Sponselee, & Schols, 2010; Rockwood & Mitnitski, 2011), many factors could adversely affect their participation in research. For example, physical (e.g., decreased gate speed, fatigue) and psychosocial factors (e.g., decreased attention, living alone) may increase respondent burden and pose methodological challenges in terms of measure selection and transportation (Ferrucci et al., 2004; McNeely & Clements, 1994). There is thus a need to know more about the specific factors that impede participation of frail older adults in research, which will be useful to design effective recruitment and retention strategies.

Thus, it is important to identify challenges that may prevent participation of frail older adults in research studies, especially those pertaining to interventions preventing adverse outcomes such as falls, disability, (re) hospitalization or institutionalization (e.g., changes in environment, organization of services, case management, exercise program, surgery, nutritional supplementation) (Ferrucci et al., 2004). Improving recruitment and retention among the frail elderly will help to determine if results from studies conducted with older adults may apply to this specific population. To the best of our knowledge, no previous study systematically reviewed the challenges encountered and the strategies used specifically with frail older adults. Therefore, the aim of this systematic review was to identify the type and the impact of challenges and strategies pertaining to recruitment and retention of frail elderly in research studies.

2. Methods

2.1. Search strategy

The methods used for this systematic review were based on a standardized protocol that was described by Pai et al. (2004).

Literature searches were performed in four databases (Medline, CINALH, Ageline, Embase). As there is no widely accepted definition of frailty in the literature, a broader search including related concepts (i.e., vulnerable, homebound) was conducted. For each database, a core set of medical subject headings was identified (cf. Appendix A). To capture any further relevant references, titles and abstracts were also searched with the following natural terms: (frail$ OR vulnerable OR homebound) AND (recruitment OR enrollment OR retention OR participation OR refusal OR attrition OR dropout). The searches were limited to articles in English or French published from January 1, 1992 through December 31, 2012. The search strategy was applied by one of the authors (VP), guided by a librarian with training and experience in the health sciences. All references were exported to Endnote with their abstracts, and duplicates were eliminated.

2.2. Study selection

All retrieved articles were independently reviewed by two of the authors of this study (BM, VP) based on their titles and abstracts. Articles were selected for inclusion if they: (1) involved adults aged 60 and older considered frail, vulnerable or housebound by the authors of the particular article; participants could be community-dwelling or hospitalized, with or without cognitive impairments. The age of sixty was set as a cut-off to include any relevant study, since signs of frailty under 65 are not rare (Santos-Eggimann, Cuénoud, Spagnoli, & Junod, 2004) and many past studies on frailty used this age cut-off (ex. Barreto, Greig, & Ferrandez, 2012; Drubbel et al., 2013; Gale, Cooper, Deary & Aihie Saver, 2014); and (2) explored barriers to and/or strategies for recruitment or retention. A barrier was defined as any obstacle or challenge related to patient conditions or methodological procedures that may interfere with recruitment and retention of participants. A strategy referred to any incentives or solutions related to patient conditions or methodological procedures designed to enhance recruitment and retention of participants. Studies that mainly focused on elderly patients (1) presenting dementia or cancer as the main diagnosis or (2) living in nursing homes were not retained. These exclusion criteria were used as it is expected that: (1) patients presenting dementia or cancer are not necessary frail; (2) different barriers and strategies may apply to the institutionalized population, which is often more "captive".