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Original Study

Older Citizens' Opinions on Long-Term Care Options: A Vignette Survey

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ABSTRACT

Background: Older citizens are directly concerned, as potential beneficiaries and informal caregivers, by access to long-term care (LTC) services matching their expectations. The aim of this research was to collect their opinions regarding LTC arrangements for a diversity of disability profiles.
Design/Setting/Participants: Mailed vignette survey in a representative population-based sample of 3133 community-dwelling persons 68 years or older residing in a Swiss region.
Measurements: All persons received a set of 10 vignettes. For each vignette, they considered 2 social situations successively: a person (1) living with an able-bodied spouse, and (2) living alone or with a spouse unable to help (resulting in 20 vignettes). Subjects selected a care setting (home, sheltered housing, or nursing home) and specified the preferred type of caregivers (spouse, professionals, or both) after community-based care options. Population estimates were based on weighted data accounting for the stratification of the survey sample.
Results: A total of 2985 participants (95.3%) expressed opinions on 55,178 vignettes (mean 18.5 vignettes, SD 4.1) Institutionalization was selected by 0.8% (95% confidence interval 0.3–1.4) of the population for the vignette of lowest disability with able-bodied spouse and 78.8% (76.1–81.6) for the vignette of highest disability and no possible help from a spouse. Continence, cognitive, and behavioral difficulties further influenced the preferences expressed for LTC options. Community-based LTC choices involved professionals mostly as a complement to informal help by the spouse, except for vignettes describing isolated moderate cognitive impairment or difficulties in instrumental activities of daily living. In these cases, most favored help provided by spouses only.
Conclusions: This survey had high acceptance. Responses to variations in the disability and social profile displayed in the vignettes suggested the validity of measurements.

The need to organize long-term care (LTC) for disabled older persons emerged during the last century as a public health question that prompted, in many countries, a multiplication of nursing homes as first response from unprepared health care systems. This soon raised concerns regarding the high cost of institutional LTC and the quality of care. Home care and help came as a secondary response, possibly less costly and more in line with what people actually want.[1] Sustainable LTC in the community, however, implies a strong investment of informal caregivers and particularly of spouses, whose ability to provide help declines with age.[2,3] Recently, intermediate solutions, such as residential care facilities, diversified the supply of LTC options.[4,5] With the aging of the post-World War II baby-boomers and increasing longevity, the organization of LTC for chronically dependent older persons will be a major challenge of the coming decades. Voices warn about the necessity of ensuring an equitable access to high-quality LTC in a time of economic crisis.[1]

The older citizens are doubly affected, as potential beneficiaries or informal caregivers, by the availability of LTC services matching their

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needs but also their expectations. At the turn of this century, Kane and Kane[6] stated that "… searching for a central tendency in older people's preferences is a worthwhile prelude to serious consideration of how to reshape policies and practices in LTC for the elderly" and they underlined the scarcity of research on this topic. According to projections by Kemper et al,[7] current retirees will need, on average, 3 years of LTC. With growing numbers of older citizens, political decisions will have to consider their opinions for the future provision of socially acceptable LTC services. Furthermore, a lack of adequate, respectful LTC response from health care systems[8,9] is likely to generate considerable avoidable costs, such as those related to inappropriate hospital days. Still, little is known regarding the limits of acceptable informal care from the disabled elders' and from their potential caregivers' perspectives. Most older persons do not discuss their preferences for LTC options in their private environment[10] and, as a population group, older persons are not consulted to determine the balance of resources invested in home care, nursing homes, and sheltered homes.

Research on older citizens' views on LTC is limited by methodological issues, including the lack of validated instruments to elicit opinions. Due to self-concerns regarding their risk of disability and to social expectations, questioning older persons about their LTC preferences is considered sensitive. Vignette survey methods have been advocated in such circumstances to facilitate distancing and help thinking on concrete stories.[11] A few studies used a limited number of vignettes or short scenarios.[12,13] Larger sets of vignettes were recently submitted to professional[14] or to Internet users.[15,16] However, they were not applied to general populations of older citizens.

The aim of this study was to test the feasibility of a large-scale consultation of community-dwelling older citizens to elicit their opinion on LTC options for a broad range of disability situations, taking into account the potential informal help from a spouse. More specifically, the effect on preference of including the following elements in disability profiles was tested: disability in activities of daily living (ADL), incontinence, cognitive impairment, and related consequences inducing particular needs.

Methods

We used data from a postal vignette survey conducted in the first semester of 2012 on a randomly selected, stratified sample of community-dwelling persons aged 68 years and older living in the Swiss region of Vaud. All individuals who had previously responded to a questionnaire on health and quality of life[17] in the frame of the Lausanne cohort 65+ (Lc65+) study[18] and were still living in the community received the self-completed vignette questionnaire (n = 3546), followed by 2 recall mailings. The Lc65+ study is a population-based observational cohort launched in 2004 to study aging and the development of frailty from the age of 65 years in the general population of Lausanne, the main city of the Vaud region. It is also used as a platform for the conduct of thematic surveys in the older population. In Winter 2011–2012, the Lc65+ study enrolled additional random samples of the community-dwelling population so as to study the quality of life over the entire Vaud region, including in the oldest age category otherwise not covered by the Lc65+ cohort.

The Vaud region counted 730,000 inhabitants, 118,000 (16.1%) aged 65 years and older, of whom 5700 (4.8%) lived in a nursing home and 21,200 (18.0%) received services from home care agencies at least once during the survey year. The Swiss universal health care insurance covers the cost of nursing and personal care provided at home or in institutions. LTC expenses related to home help for instrumental ADLs (IADLs) and nursing home accommodation are charged to the beneficiaries or covered by the state for low-income elders.

Table 1
Vignettes Description (Labels Not Shown to Respondents)

1 (Moderate cognitive)
Mrs M. has good mobility and is independent for all activities of daily life. However, for some time, she happens to forget the little things, such as her appointment to the doctor. She is making notes all on scraps of paper. She is comfortable in familiar situations or environments, but sometimes has difficulty when faced with new situations or with environments that she does not know. She realizes it, and this generates much anxiety.
2 (IADL)
Mr T. suffers from respiratory disorders. Despite this, he retains his autonomy in personal hygiene, and washes and dresses himself. He moves slowly, but without help, and he happens to catch a bus to get into town. However, he must be helped to prepare meals, to shop for groceries, and to clean his house because he quickly becomes short of breath.
3 (IADL, Moderate cognitive)
Mrs R. has no physical difficulty, but has memory losses. For some time, she has been disorganized and she is eating poorly. She must be helped to clean her house, to shop for groceries, and to prepare meals. Although she is able to wash herself, someone must ensure that she regularly showers.
4 (Moderate BADL)
Mr V. suffers from neurological disorders. It is important to him that people know that he has all his mind, his problem is physical. He needs help to prepare meals, to clean his house, and to shop for groceries. He must also be helped to get out of bed in the morning, to wash, and to dress, but he can then move inside and get up from a chair alone. He is autonomous to eat and to drink.
5 (Moderate BADL, Urine incontinence)
Mrs P. had a stroke. She cannot clean her house, shop for groceries, or prepare meals. She re-learned how to eat without help, but she needs help to get out of bed in the morning, to bathe, and to dress. She can get up from the chair and move inside, using a cane. She suffers from accidental loss of urine that she cannot handle alone, but she manages to hold her stool.
6 (Severe BADL)
Mr D. suffers from neuromuscular disorders. He must be assisted in all ADLs, including to eat, to stand up, and to sit down. He can move inside alone, using canes. He is not incontinent but needs assistance to use the toilet.
7 (Moderate BADL, Urine and fecal incontinence)
Mrs L. had a stroke. She cannot clean her house, shop for groceries, or prepare meals. She re-learned how to eat alone, but she needs help to get out of bed in the morning, to bathe, and to dress. She can get up from a chair and move inside, using a cane. She suffers from frequent loss of urine and feces that she cannot manage alone.
8 (Severe BADL, Aggressiveness)
Mr H. suffers from neuromuscular disorders. He must be assisted in all ADLs, including to eat or to settle in his electric wheelchair with which he moves alone inside. He is not incontinent but needs assistance to use the toilet. He resents his dependence and is often very aggressive with people who care for him.
9 (Severe BADL, Severe cognitive, Safety)
Mrs F. suffers from a neurological disease. She needs help with all ADLs, including to eat and to drink. She is no longer able to name objects and seems lost. She has retained good ability to move but, because of the anxiety she feels, she frequently wanders aimlessly. She sometimes gets lost when outside of her home.
10 (Severe BADL, Severe cognitive, Aggressiveness)
Mr S. suffers from a neurological disease. He is constantly lying in bed or sitting in his chair. He needs help with all ADLs, including to eat and to drink. He is no longer able to name objects and seems lost. He is often agitated and has an aggressive behavior characterized by insults, swearing, hitting, scratching, and biting.