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Original Study

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

Brigitte Santos-Eggimann MD, DrPH, MPH*, Lionel Meylan MSc, MAS

Lausanne University Hospital, Institute of Social and Preventive Medicine, Lausanne, Switzerland

A B S T R A C T

Keywords:

Long-term care
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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.

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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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* Address correspondence to Brigitte Santos-Eggimann, MD, DrPH, MPH, Unité des services de santé, Institut Universitaire de Médecine Sociale et Préventive, Biopôle 2 - Route de la Corniche 10, Lausanne 1010, Switzerland.

E-mail address: Brigitte.Santos-Eggimann@chuv.ch (B. Santos-Eggimann).

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needs but also their expectations. At the turn of this century, Kane and Kane⁶ 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 environment¹⁰ 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 professional¹⁴ 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 life¹⁷ in the frame of the Lausanne cohort 65+ (Lc65+) study¹⁸ 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.

The protocol of this study has been approved by the Ethics Committee for Human Research of the Vaud region.

Vignette Design and Administration

A set of 10 vignettes was designed to present situations entirely defined by impairments that induce needs for personal care or help (Table 1). The vignettes' wording was concise, and used the third person and the present tense. The number of vignettes was determined by the aim to collect respondents' opinions on a broad range of situations while avoiding fatigue. Therefore, a limited number of disability dimensions were selected by the 2 authors among factors likely related to institutionalization in old age.¹⁹ Four components were considered in the writing of the vignettes. ADL disability: none (in first vignette), mild (IADL only), moderate (bathing, dressing, getting out of bed, which implied help limited to mornings and evenings) and severe limitations (transferring, using toilets, eating, which implied help during the day). Incontinence with explicit need for help: urinary only or urinary and fecal. Cognitive impairment: none, moderate (inducing anxiety or a need for supervision in ADLs), or severe (inducing safety concerns or with aggressiveness toward caregivers). Aggressiveness also was considered in one vignette as a problem complicating a situation of physical impairment without cognitive deficit. The set of 10 vignettes was selected as (1) to present a plausible mix of problems in each vignette (eg, severe cognitive impairment is likely associated with severe ADL impairment), and (2) to permit comparisons within subsets of vignettes sharing a fixed part and differentiated by one variable component (eg, severe basic ADL [BADL] limitations with and without aggressiveness). To control the gender effect, the 10 vignettes presented the situation of Mr or Mrs X, alternately. Two versions of the questionnaire (beginning with one gender or the other) were randomly allocated in the study sample. To maximize the focus on disability-related needs, the age was not specified; very limited information was provided on the underlying morbidity, only when it helped to explain the disability profile; and, finally, the socioeconomic category of Mr or Mrs X, could not be derived from the vignette presentation.

The same set of 10 vignettes was submitted to all individuals at the end of a questionnaire on care. A brief introduction stated: "In this final section, you will find 10 stories of people who, due to health problems, have difficulties in some routine activities. In each case, we want to know what arrangement seems preferable to you: where should the person live? Who should help him or her in daily life? We ask you to imagine first that the person lives with an able-bodied spouse, and then that the person lives alone or with a spouse who cannot help." Taking into account potential informal care by a spouse (Spouse+ or Spouse-) after each disability profile, respondents were therefore asked to provide opinions on 20 final vignettes.

Respondents first selected a care setting for Mr or Mrs X, among 3 options: the usual home, a sheltered home, or a nursing home. One single response was expected. Sheltered housing was previously defined as "a private housing with (1) architectural adaptations permitting access to individuals with reduced mobility, (2) an alarm installation with response to calls, eg, in case of falls, and (3) community spaces within the building or in immediate proximity, allowing exchanges and various animations; help (home cleaning, meals-on-wheels) and care may be provided in sheltered housing by home care agencies."

When they had selected the usual home or a sheltered housing for a Spouse+ vignette, respondents further specified the preferred type of help providers: the spouse, professionals, or both. Professional help was explicitly included in community-based care options for the Spouse- vignettes. When a community-based option was selected for the first vignette, showing a person without ADL disability but with

moderate cognitive impairment generating anxiety, respondents could also indicate that no help was needed.

Analyses

We verified the acceptance of the vignette survey based on the proportion of survey participants who expressed their opinion on LTC options. Multiple responses combining usual home and nursing home options for the same vignette were considered as missing. When 2 close options had been selected (eg, usual home and sheltered housing, or shelter housing and nursing home), however, both were recorded. Bivariate analyses compared characteristics of respondents and nonrespondents, using data collected in the Lc65+ follow-up and the health and quality of life survey. These included gender, age in 5 categories, highest achieved level of education, reported financial insecurity (financial embarrassment or difficulties to make ends meet), chronic diseases diagnosed by a physician (treatment or disturbance in the past 12 months for hypertension, coronary artery disease, other cardiac disease, cerebrovascular disease, diabetes, chronic pulmonary disease including asthma, osteoporosis, arthritis, cancer, gastroduodenal ulcer, depression, or Parkinson disease), difficulty walking 100 m or inside, BADL difficulty (bathing, dressing, transferring, using the toilet, or eating), reported cognitive difficulty (memory troubles affecting the daily life or difficulty concentrating or difficulty making decisions, lasting 6 months or more), and urine incontinence lasting 6 months or more. Based on the same set of characteristics, respondents who never selected a nursing home as a preferred care setting were compared with respondents who selected this option for at least one vignette. Further analyses described the mean number of vignettes completed by the individuals who took part in the vignette survey and the proportion of missing responses to each of the 20 final vignettes.

Analyses of population preferences for LTC options were performed for each of the 20 final vignettes on weighted data, taking into account the sampling design. We present results for the preferred care setting and for the type of care providers, successively, in 6 subsets of vignettes displaying the effect of (1) increasing level of ADL disability: vignettes 2, 4, and 6; (2) incontinence: vignettes 4, 5, and 7; (3) aggressiveness in cognitively intact persons: vignettes 6 and 8; (4) moderate cognitive difficulties: vignettes 2 and 3; (5) severe cognitive difficulties with concerns for security: vignettes 6 and 9; and (6) severe cognitive difficulties with aggressiveness: vignettes 8 and 10. All analyses were conducted using Stata 14.0 (Stata Corp, College Station, TX).

Results

The survey questionnaire was returned by 3133 individuals (88.4% of 3546), of whom 148 (4.7%) stopped before the vignette section and 2985 (95.3%) expressed their opinion on one or more vignettes (final response rate 84.2%). Table 2 shows that nonrespondents were older, lived more frequently without a spouse, had a lower level of education, and reported more frequently difficulties in walking or in BADLs. However, their profile did not differ significantly regarding gender, financial insecurity, the number of reported chronic medical conditions, incontinence, or self-reports of cognitive difficulties.

Respondents to the vignette survey completed a total of 55,178 (92.4%) of 59,700 vignettes, giving their choice for an average 18.5 (SD 4.1) of 20 vignettes. The mean was 9.2 (SD 2.2) for the 10 Spouse+ vignettes and 9.2 (SD 2.0) for the 10 Spouse- vignettes. Missing responses did not concentrate on specific vignettes. They ranged from 6.4% to 8.1% for the Spouse+ and from 5.8% to 8.9% for the Spouse- vignettes. In 98.5% of all vignettes, respondents complied with instructions to select one single care option. Most of the recorded double choices concerned Spouse+ vignettes (80.2%, versus 19.8%

Table 2
Characteristics of the Study Population (Weighted Data) and of Respondents Versus Non-Respondents to the Vignette Survey

	Population Weighted %	Sample				P
		Respondents, n = 2985, 95.3%		Nonrespondents, n = 148, 4.7%		
		n	%	n	%	
Age, y						
68–69	14.6	639	21.4	23	15.5	<.001
70–74	27.6	1255	42.0	51	34.5	
75–79	22.6	784	26.3	39	26.3	
80–84	17.0	166	5.6	18	12.2	
85+	18.2	141	4.7	17	11.5	
Gender						
Women	57.4	1645	55.1	93	62.8	.065
Spouse						
Yes	57.9	1785	60.4	42	29.0	<.001
Education						
Compulsory	27.4	612	20.6	47	32.9	.006
Apprenticeship	38.0	1206	40.7	48	33.6	
Secondary, professional	23.1	722	24.4	28	19.6	
Tertiary	11.5	423	14.3	20	14.0	
Financial insecurity*						
Yes	37.9	1108	37.2	60	42.0	.254
Chronic diseases [†]						
0	20.3	752	25.4	29	19.9	.136
1	36.3	1061	35.8	49	33.6	
2+	43.3	1152	39.8	68	46.8	
Walking difficulty [‡]						
Yes	22.6	381	12.8	37	25.9	<.001
BADL difficulty [§]						
Yes	24.2	481	16.2	41	29.5	<.001
Cognitive difficulty						
Yes	17.0	480	16.3	31	21.8	.083
Urine incontinence [¶]						
Yes	17.9	414	14.1	17	12.0	.485

*Reported financial embarrassment or difficulties making ends meet.

[†]Reported treatment or disturbance in the past 12 months for hypertension, coronary artery disease, other cardiac disease, cerebrovascular disease, diabetes, chronic pulmonary disease including asthma, osteoporosis, arthritis, cancer, gastroduodenal ulcer, depression, or Parkinson disease, diagnosed by a physician.

[‡]Reported difficulty walking 100 m or inside.

[§]Reported difficulty bathing, dressing, transferring, using the toilet, or eating.

^{||}Reported memory troubles affecting daily life or difficulty concentrating or difficulty making decisions, lasting 6 months or more.

[¶]Reported urine loss lasting 6 months or more.

Spouse–). Respondents hesitated essentially between usual home and sheltered housing options (91% of all double choices) and in relation to vignette 1 (40% of all double choices). In the Spouse+ circumstance, double choices were also more frequent for the vignettes 2 and 3.

One in 5 respondents (21.6% of the population, 95% confidence interval 19.0–24.2) never selected the nursing home option across the 20 vignettes. This behavior was more frequently found in men and in those with financial insecurity. Like nonresponse, it was also associated with lower education, living with a spouse, and reporting walking or BADL difficulties, but not with the reported number of chronic diseases, incontinence, or cognitive difficulties (Table 3).

Vignettes' Characteristics and Preferences for the Care Setting

The distribution of preferred care settings differed according to the vignette social situation (Figure 1, columns a and b). It reflected the severity of ADL disability (cf. subset 1) as well as all other dimensions that determined needs for help described in the stories (cf. subsets 2–6). As shown in subset 1, choices for the usual home declined with increasing severity of ADL disability. In the Spouse+ situation, IADL limitations did not justify other options than home care. When BADLs were moderately compromised, a quarter of the population considered alternative options, mostly sheltered housing. For severe BADL disability, most preferred alternatives to the usual home. In Spouse– circumstances, 61% of the population considered home care as their preferred choice when disability was limited to IADLs, one-third

opting for sheltered housing. Fewer than half still selected home care with moderate BADL disability, one-quarter only in case of severe BADL alteration.

When urine incontinence complicated moderate BADL disability (subset 2), preferences for care in the usual home dropped from three-quarters of the population to less than half in the Spouse+ situation; the addition of fecal incontinence further reduced this choice to one-third, almost half of the population selecting the nursing home option. Incontinence was also a major determinant of the choice for nursing home in the Spouse– situation, with nearly half of the population selecting this option for moderate BADL disability with urine incontinence, and more than 60% when mixed incontinence was described in the vignette.

The first vignette (not shown in Figures 1 and 2) described the limit-situation of an autonomous person with early, compensated cognitive troubles that generated anxiety. Choices for the care setting were almost identical to those expressed regarding the second vignette (IADL impairment only): in the Spouse+ situation, 94.6% selected usual home, 14.1% sheltered housing (including double choices), and fewer than 1% nursing home options. In the Spouse– situation, proportions were 62.0%, 31.4%, and 9.0%, respectively. When moderate cognitive impairment was added to IADL difficulties, few changes were observed in the preferred care setting, particularly in the Spouse+ circumstance, as shown in subset 4.

However, in case of severe BADL disability, severe cognitive impairment increased the preference for institutionalization. Most of

Table 3

Characteristics of Respondents to the Vignette Survey who Selected a Nursing Home as the Preferred LTC Option for at Least 1 Vignette Versus for None

	Nursing Home Choice				P
	At Least 1 Vignette, n = 2377, 80.7%		No Vignette, n = 569, 19.3%		
	n	%	n	%	
Age, y					
68–69	528	22.0	111	19.1	.058
70–74	1016	42.3	239	41.1	
75–79	630	26.2	154	26.5	
80–84	122	5.1	44	7.6	
85+	107	4.5	34	5.8	
Gender					
Women	1406	58.5	239	41.1	<.001
Spouse					
Yes	1407	59.0	378	66.4	.001
Education					
Compulsory	474	19.8	138	24.0	<.001
Apprenticeship	950	39.8	256	44.6	
Secondary, professional	619	25.9	10	17.9	
Tertiary	346	14.5	77	13.4	
Financial insecurity*					
Yes	871	36.3	237	41.1	.033
Chronic diseases†					
0	615	25.8	137	23.7	.255
1	861	36.1	200	34.5	
2+	910	38.1	242	41.8	
Walking difficulty‡					
Yes	269	11.2	112	19.4	<.001
BADL difficulty§					
Yes	354	14.8	127	22.2	<.001
Cognitive difficulty					
Yes	387	16.3	93	16.3	.971
Urine incontinence¶					
Yes	335	14.1	79	13.9	.897

*Reported financial embarrassment or difficulties making ends meet.

†Reported treatment or disturbance in the past 12 months for hypertension, coronary artery disease, other cardiac disease, cerebrovascular disease, diabetes, chronic pulmonary disease including asthma, osteoporosis, arthritis, cancer, gastroduodenal ulcer, depression, or Parkinson disease, diagnosed by a physician.

‡Reported difficulty walking 100 m or inside.

§Reported difficulty bathing, dressing, transferring, using the toilet, or eating.

||Reported memory troubles affecting daily life or difficulty concentrating or difficulty making decisions, lasting 6 months or more.

¶Reported urine loss lasting 6 months or more.

the population chose this option, including in the Spouse+ situation, when the vignette described a risk of getting lost, raising concerns for safety (subset 5), and three-quarters selected the nursing home option when severe cognitive impairment was associated with aggressiveness, irrespective of the social situation (subset 6). Aggressiveness of highly dependent persons without cognitive impairment also determined a higher level of preference for the nursing home option, irrespective of the social situation (subset 3).

Vignettes' Characteristics and Preferences for Caregivers

For the first 2 vignettes characterized, respectively, by autonomy in ADLs and disability limited to IADLs, more than half (58.4% and 54.3%) of the population that had selected the usual home option preferred care provided only by spouses. For all other vignettes, displaying moderate or severe BADL disability, most preferred care by the spouse and professionals (Figure 2). Care provided at usual home only by professionals was selected by fewer than 8%, except for the vignettes including incontinence, aggressiveness, and severe cognitive impairment (11.4% to 15.8%). When sheltered housing was the preferred setting (Figure 2b), a similar trend was observed with a shift toward

care less frequently provided only by spouses and more frequently provided only by professionals.

Discussion

This study provides an insight on older citizens' capacity to express their views regarding LTC options for a broad range of disability situations. This vignette survey had a high completion rate, showing good acceptance of the method. The mean number of vignettes completed by participants was close to the maximum. Missing opinions did not concentrate on specific vignettes and were less frequent than reported in other studies.^{13,20,21} Results pointed to systematic preference for community-based options in one-fifth of the study population, irrespective of the level of needs and the social situation. Although this finding may reflect an unrealistic appreciation of the needs, according to Tucker et al¹⁴ only 55% of a panel of professional experts considered institutionalization as the most appropriate option in case of severe ADL and cognitive disability with challenging behavior. Nevertheless, we observed that respondents who never selected the nursing home option shared several characteristics with the small group of persons who responded to the care survey but did not complete the vignette section. Expressing differentiated views regarding LTC options may be more difficult for elders of lower economic and educational status, experiencing difficulties in the ADL, and among persons living with a spouse, particularly in men.

Our results indicated that older citizens' preferences for the setting of LTC are modulated by the level of need, with distinct effects of the severity of ADL disability and of specific dimensions such as incontinence, cognitive difficulties, or behavioral challenges. Most previous studies relied on a single, abstract question,^{21–25} and asked individuals about preferences for themselves in case of a hypothetical situation of disability without providing detailed information regarding the nature of disability. Effects on LTC preferences of increasing severity in a single dimension of disability were nevertheless reported by Guo et al²⁶ for BADLs, and by Matsumoto et al²⁷ for walking impairment. Some studies contrasted situations that differed simultaneously in several dimensions^{20,28–31} and, therefore, could not disentangle the specific effects of multiple aspects included in disability profiles. Only a few studies described preferences for others,^{12,13,15} or more precisely for older relatives.^{16,32} A recent vignette experiment controlling for socioeconomic circumstances confirmed a specific effect of the severity of functional decline on the choice for retirement communities versus the usual home in situations involving an unknown person.¹⁵ Despite the diversity of methodological approaches and their limitations, the severity and expected duration of disability situations presented to older persons, or inclusion of dementia in their scenario, increased the proportion of older persons in favor of institutionalization.

Although a limited number of studies integrated some information on social environment,^{15,16,21} it was not conceptualized as a source of informal help except in the survey of professionals' preferences conducted by Tucker et al.¹⁴ In our study, for all vignettes, higher proportions of the population preferred care in the usual home when the situation concerned a person living with an able-bodied spouse, illustrating the importance of possible informal help within the household. Choices may be more difficult when they imply 2 persons and their interrelationships. Although double choices were not expected, a small proportion of respondents could not decide, mostly between usual home and shelter housing options. Interestingly, double choices were more frequent for our vignettes displaying a cognitively intact, moderately disabled person living with an able-bodied spouse. Moving from the usual home to sheltered housing is likely to have both positive and negative effects on able-bodied spouses, as it alleviates the burden of care at the price of a major environmental change. The balance may be less favorable, and the decision more

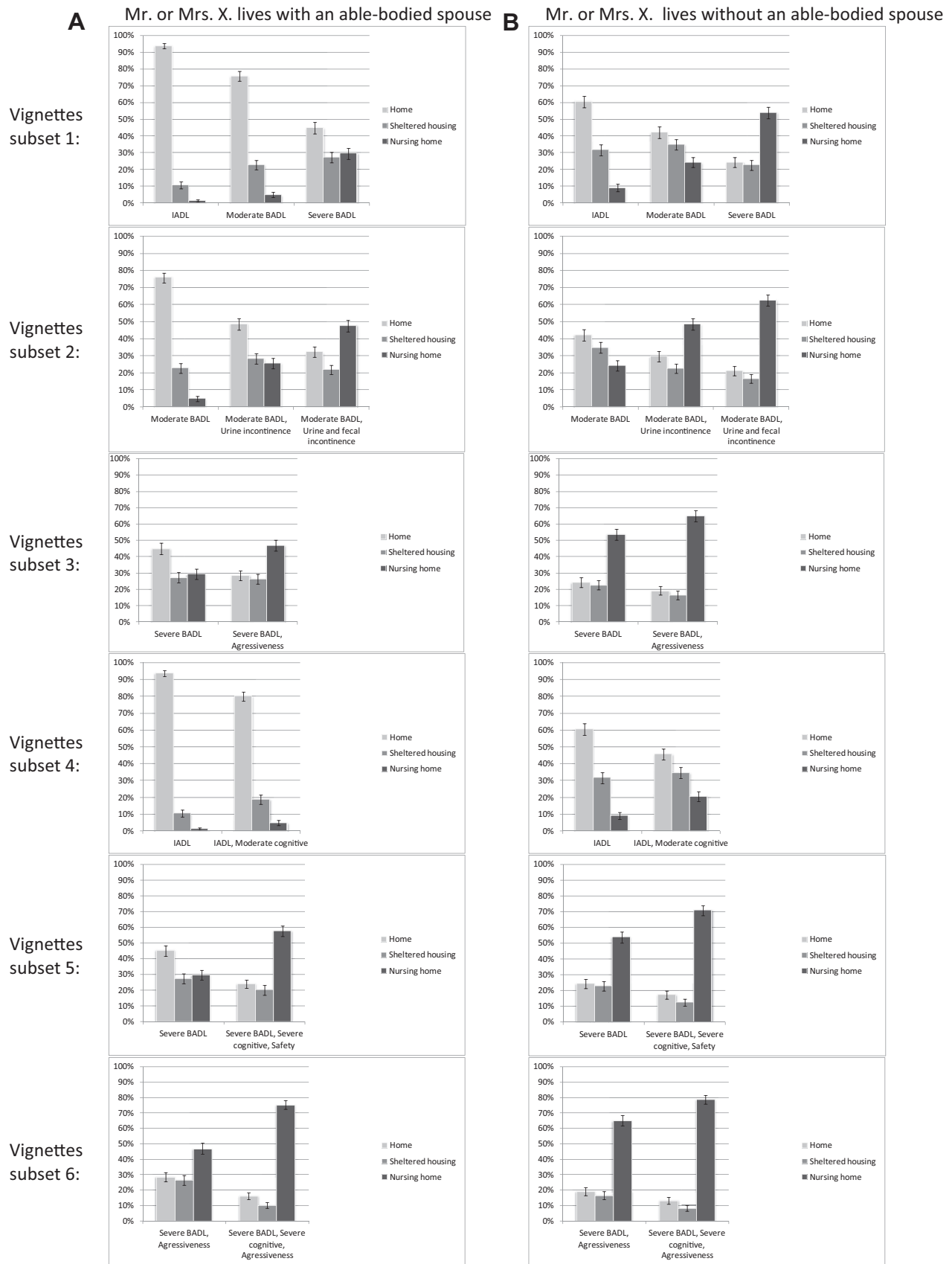


Fig. 1. Choice for care settings according to the disability profile and potential help from a spouse.

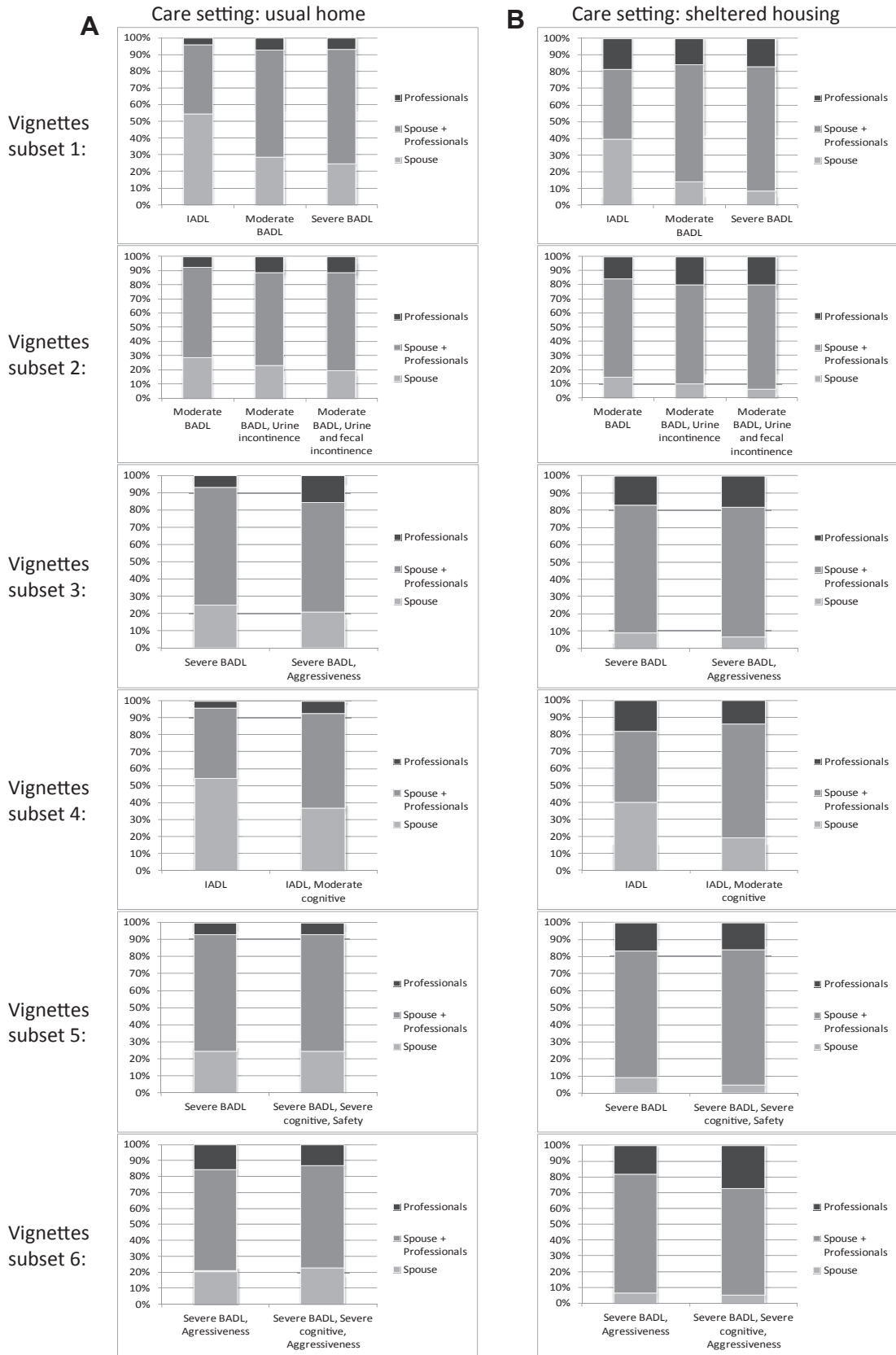


Fig. 2. Choice for caregivers according to the disability profile and type of community-based setting (Mr. or Mrs. X. lives with an able-bodied spouse).

difficult, in case of moderate disability, when the burden of care is still relatively light.

Finally, results indicated strong expectations of spouses' involvement in LTC when community-based options were selected. If the vignette specified that an able-bodied spouse was present in the household, the choice of exclusively formal care was marginal including in the most severe disability profiles. However, most preferred mixed care provided by spouses and professionals for all vignettes, except when no help was needed in ADLs or when disability was limited to IADLs in a cognitively intact person living in the usual home. These observations suggest that, from the older population's perspective, spouses should not be left alone with caring responsibilities when help is needed in BADLs or when cognitive decline is associated with ADL disability. Although some studies asked for preferences between informal and formal care, they usually did not propose mixed support as a possible choice.^{13,20,23,31} Pinquart and Sörenson³³ found a preference for exclusive use of informal support in 15.2% of a US sample and 24.9% of a German sample of an older, nondisabled community-dwelling population when other options were mixed or professional care, including in institutions.

Singular strengths of this study were a large, representative population-based sample of elders, high participation, use of vignettes favoring older citizens' expression with some distance, a large range of disability situations submitted to their appreciation, a capacity to isolate the effect of specific aspects of disability in analyses, control of gender effects by design, consideration for the social situation, and questions asked both on care location and providers. The high response rate in our survey was probably explained by a relationship of trust established over years in the local population with the conduct of the Lc65+ study. Previous research in this field was scarce and limited by small or convenience samples,^{9,12,25,28,31,34,35} low participation,^{16,27} conduct in population groups with specific cultural^{20,28,30,31,36} or health^{9,12,13,25,28,34} characteristics, survey methods likely to induce a selection bias in older populations (eg, data collected via the Internet),^{15,16} failure to provide practical information to respondents regarding disability needs and social circumstances, or narrow focus on a small number of vignettes. In this context, 2 studies provided promising methodological innovations. Tucker et al.¹⁴ designed a set of 14 vignettes that covered a broad range of disability situations, mixing demographic, functional, and social characteristics. However, these vignettes were limited to older persons with dementia and were not submitted to older citizens, but to professionals. Caro et al.¹⁵ used an experimental method, generating a large number of vignettes based on 5 health and socioeconomic dimensions and randomly allocating subsets of 4 vignettes to survey participants. Unfortunately, disability was described by one dimension only (BADL) and LTC options were reduced to staying at home or moving to residential facilities. Application of this method to study the effect of multiple aspects of the disability profile that determine the needs for LTC would be difficult. Indeed, random generation of disability vignettes would produce unlikely combinations, like autonomy in ADLs with severe cognitive impairment, making it difficult to express opinions. Therefore, following Tucker et al,¹⁴ we rather designed a limited set of vignettes presenting plausible combinations of multiple aspects of disability and submitted it to the whole survey sample.

Limitations are related to our study population. The survey was conducted in a geographically defined region and results may not be generalized to other places as local conditions may influence preferences.^{20,37} Economic resources may influence choices for LTC options where universal access to care is not guaranteed. Furthermore, participants in this survey live in the community and this likely reflects, in most cases, their preferences. Older persons who live in institutions were not included. They may have other preferences. We do not know the extent to which life in a nursing home results from choices and

whether it changes older persons' preferences for LTC options. It would be particularly difficult to ask older persons who live in institutions their LTC preferences for a range of disability profiles, for ethical reasons and because severe cognitive impairment is highly prevalent in nursing homes. However, by neglecting their opinions, we introduced bias in measurement of older citizens' preferences. The effect of this bias on results should nevertheless remain modest, as less than 5% of the older population in the study region lives in institutions. Finally, despite their importance in some situations, we did not include the potential help of nonspouse caregivers as a dimension in our vignettes because nonspouse informal caregivers may be very diverse, both in their relationship with the dependent older person and in the type and intensity of help or care that they may provide.

As LTC provision requires long-term investment and planning from the authorities, it is important to have reliable tools to assess beneficiaries' opinions so as to match their expectations. This survey demonstrates the feasibility of collecting community-dwelling older citizens' choices regarding different arrangements through vignettes. We assume that this methodology also could be extended to services such as meals-on-wheels or monitored alarm systems so as to investigate added value and/or acceptance of such assistance in different places.

From a clinical perspective, many elements come into play when a decision about the most suitable LTC option must be made in individual cases. Because vignettes oversimplify this complexity, their contribution in the clinical decision-making process should be considered only as partial and at no time as decisive. Therefore, results from vignette surveys certainly reflect general opinions in the population rather than individual preferences. Field professionals should nevertheless be aware of citizens' opinions, as they might differ from their own perception.

Conclusions

Older citizens' preferences for LTC options should be collected in other populations to investigate their stability across countries and to study contextual factors that may influence choices. Further analyses will provide an insight on individual factors, such as demographic, health-related, social, or economic, that may explain choices. Interactions with the older population seem feasible and they should become a key element in improving our planning of LTC services.

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