

Influence of Proxies on the Reported Frequency of Falls, Fear of Falling and Activity Restriction in Older People

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Abstract

Introduction: In older populations, the help of a third person may be necessary for a certain number of individuals in order to fill in questionnaires. The influence of this assistance on the collected information can raise questions, among others concerning the concordance between the information provided by the persons themselves and by their proxies, or the introduction of a potential bias. Our study's objective is to examine, among older people, the differences in the reported frequency of falls, fear of falling and activity restriction due to fear of falling, according to the fact that people had filled in a questionnaire with or without the help of a third person. **Methods:** The data used come from the secondary analysis of a cross-sectional survey using a self-administered questionnaire and conducted in 2006 in a Belgian semi-rural town among non-institutionalised persons aged 65 years and over. **Results:** Among the 501 questionnaires, 16.4% were filled in with the help of another person. In bivariate analysis, the persons who needed help reported fall history, fear of falling and activity restriction significantly more often. In multivariable analysis, when considering concurrently the covariates (sex, age, living alone and fall history for fear of falling and for activity restriction), the influence of having received help to fill in the survey was only significant for activity restriction. **Conclusion:** Our study shows that it is important to know whether or not a person has received help to fill in a questionnaire. This can actually influence the reported frequency of certain outcomes, even, for activity restriction, when considering simultaneously the effect of other covariates. Given the current and future ageing of our popula-

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tions, it seems that more extensive exploration is needed of the influence of proxies on the collected information about falls, fear of falling and activity restriction among older people.

Keywords

Accidental Falls, Fear of Falling, Activity Restriction, Proxies, Older People

1. Introduction

The proportion of older people in our populations is significant. In 2013, 8% of the world's population, and 16% of the European population, were aged 65 years or over [1]. This ageing of the populations will continue in coming years [2]. "Proxy data" refers, according to Lynn Snow *et al.* ([3], page 1678), to "those collected from someone who speaks for a patient who cannot, will not, or is unavailable to speak for him or herself". The use of a proxy may be necessary in various circumstances, among others when surveying older people [4], among whom data collection may be difficult due to physical, sensory or cognitive impairments [4]. The ageing of the population is accompanied by an increase in the number of older people who are unable to respond to surveys themselves [5] and the older that respondents are, the greater the need for "proxy respondents" [6]. Based on other studies, Magaziner *et al.* estimated in 1997 that the proportion of older people unable to provide the information sought could be above 20% among non-institutionalised older people, 40% among hospitalised older people and 50% among older people living in nursing homes [4]. Proxies can be involved either by responding "for" or "on behalf of" the older person; or by providing additional data [6].

The use of proxies and the data they provide allows, among other things, the size of samples to be increased [7] [8] along with their representativeness of the populations studied [6] [7], in addition to extending the periods people can be monitored for as the ability of the people to respond no longer prevents data from being collected [6]. This also allows that the most vulnerable people or people in the poorest health [5], or people with cognitive impairments whose quality of life may be the most affected by illness [9], no longer have to be excluded from surveys. However, the use of proxies can raise questions. For example, proxies may be unable to answer questions about certain patient's medical problems [10]. In addition, when they answer questions, the extent to which the information they provide matches the information the respondents themselves would have provided, can be questioned [5].

The agreement between the information provided by the persons themselves and by their proxies varies, among others, depending on the health aspects surveyed and the items most specifically targeted within these aspects. In particular, it has been documented that the agreement varies according to the pathologies considered [7] [8] [10]. For example, there is greater agreement for diabetes [7] [8] [10] or amputations [8] and weaker agreement for arthritis [8] [10] or nervous and emotional problems [7]. For functional status, the agreement can range from moderate to substantial, and even be almost perfect in certain cases [7] [8] [11] [12]. As with chronic pathologies however, it does vary within different daily living activity groups, depending on what is being examined [7] [8] [11]-[13]. For health symptoms, the agreement is lower overall even though it is higher for certain symptoms that are more easily observed and expressed [7]. It is also lower for other physical health measures [11], for subjective health [14], or for generic measures of health status, such as the "Short-Form-12 Health Survey" (SF-12) scale [15]. For psychological well-being, depression and cognitive status measures, proxy data appears overall to be moderately to well correlated with data from the people themselves, according to two studies [16] [17]. Neumann *et al.*, who reviewed various results, reported on the contrary that the agreement was moderate to low for symptoms of depression and psychological well-being [6].

Depending on the health issues or areas being considered, proxies may moreover over- or under-report. Generally, they tend to overestimate cognitive capacity [4] [16] and underestimate functional status [7] [11]-[14]; even if certain studies show that, depending on the activities being considered, functional capacities may be over- or underestimated [4] [8]. Magaziner *et al.* observed that proxies tend to over-report certain chronic conditions [7] and underestimate health status [11]. Another study reported that, according to the health issues studied, some may be over-reported (e.g. family psychiatric history, memory problems, etc.) and other may be under-reported (head injury, person has never consumed alcohol, etc.) [10]. For broader measures of health status, proxies overall under-assess patients using the SF-36 [9] [18] and SF-12 [15] scales. Proxies also appear to un-

derestimate the well-being of older people [16], their health-related quality of life [19] and to report more depressive symptoms and illnesses [6]. However, it should be noted that in the study by Vuorisalmi *et al.* [14], older people assess their health status more negatively than proxies.

Falls are a frequent problem in older populations. Between 30% and 60% of non-institutionalised older people fall at least once annually [20]. While falls may have physical repercussions that can be significant [20] [21], they can also lead to psychological consequences or “difficulties” [22], including fear of falling and activity restriction due to fear of falling [22]. Fear of falling affects between 20.8% and 56.7% [23]–[28], and activity restriction concerns around 40% [23] [28] of older people; and both also affect older people who have not fallen [28] [29]. With respect to falls, Higashi *et al.* observed greater concern by proxies than by the older people themselves [15]. Another study, which involved a very small sample of adults with intellectual impairments, showed substantial to perfect agreement between the data from the people and their “key caregivers” for prior history of falls, fear of falling and activity restriction due to fear of falling [30]. As we can see, the reported results do not lead to the same conclusions. Moreover, the Prevention of Falls Network Europe (ProFaNE) recommends, among other measures, the evaluation of the practicality, validity and reliability of data provided by proxies regarding falls [31]. We previously described the frequency of fear of falling and of related activity restriction, and the characteristics of the persons affected by these two issues [32]. This study concerned however only people who answered themselves to the survey [32]. Our aim here is thus to examine, within a sample of non-institutionalised older people, the differences in the reported frequency of falls, fear of falling and activity restriction due to fear of falling, according to the fact that people had filled in a questionnaire with or without the help of a third party.

2. Methods

2.1. Survey—Participants

The data presented come from the secondary analysis of a cross-sectional survey conducted between April and August 2006 in the semi-rural town of Fontaine l’Évêque (Wallonia—Belgium) and which targeted all people aged 65 years and over living at home. The primary aims of this study were to describe the frequency, circumstances and consequences of falls, the frequency and circumstances under which people feared falling, the frequency of activity restriction due to fear of falling and the types of activities that were reduced, as well as modifications made to homes or which would be needed to reduce the risk of falling. A self-administered questionnaire was sent by the local administration to 2812 people identified as being eligible to take part in the survey. A reminder was published in the local press to increase the participation rate. Five hundred and fourteen questionnaires were returned (participation rate: 18.3%), of which 13 were excluded (age could not be calculated ($n = 6$) or aged under 65 years ($n = 1$)—institutionalised ($n = 2$)—unable to walk ($n = 1$) or in a wheelchair ($n = 2$)—did not answer any questions ($n = 1$)). The flow-chart of the study is presented in **Figure 1**.

2.2. Data Collection

Various pieces of data were collected. Only those considered in this article are presented in detail.

2.2.1. Independent Variable

Participants were notified that they could, if necessary, be helped by a third party in order to fill in the questionnaire. If this was the case, they were asked to indicate this. On the basis of this data, the “*help from a third party*



Figure 1. Flow-chart of the study.

to fill in the questionnaire: Yes—No” variable was created.

2.2.2. Dependent Variables

Three outcomes were analysed: *fall history*, *fear of falling* and *activity restriction due to fear of falling*. These were assessed through the following questions: 1) “Have you fallen within the past 12 months? Yes—No”, 2) “Are you afraid of falling? Yes—No”, 3) “Have you stopped or do you less frequently carry out some of your activities due to fear of falling? Yes—No”. All participants were asked the question on the activity restriction, whether or not they were afraid of falling.

2.2.3. Covariates

Sex, age in three categories (65 - 74 years, 75 - 84 years or 85 years and over) and living alone (Yes—No) were considered as covariates. The number of falls within the past 12 months (0, 1, 2 and more) was also taken into account when examining fear of falling and activity restriction due to fear of falling.

2.3. Statistical Analyses

The sample and the various outcomes studied were described through proportions. The Chi-square and the Chi-square for trend, when applicable, were used to study associations between variables. To measure the strength of these, the Odds Ratios (ORs) and their 95% Confidence Intervals (95% CIs) were calculated. Logistic regression models were constructed to examine whether filling in the questionnaire with or without the help of a third party was associated with the three aspects studied when taking into account the covariates, whose entry in the models was forced. The adjusted ORs derived from the models and their 95% CIs are shown, alongside the p-value of the Wald’s Chi-square. Model fit was verified using the Hosmer and Lemeshow’s test and by residual analysis. Given the existence of significant interaction between age and living alone on fall history, for this, the model is presented adjusting for this interaction in addition to the other covariates considered. The analyses were done with the SPSS Statistics 20.0 and EpiInfo 3.3.2 software, and using the statistical significance threshold of 0.05.

3. Results

3.1. Description of the Sample (Table 1)

The characteristics of the participants are presented in **Table 1**. Women comprised the majority of the sample. People aged 65 - 74 years and 75 - 84 years represented respectively close to half of the total sample and four out of ten people lived alone. The aid of a third party when filling in the questionnaire was reported in 16.4% (82/501) of cases. In comparison with people who filled in the questionnaire on their own, those who received help were significantly older, more often women and lived significantly more frequently alone.

In the total sample, 34.1% (170/498) of people reported one or more falls in the past 12 months, 61.8% (295/477) said they were afraid of falling and 37.6% (171/455) had reduced some of their activities due to fear of falling.

3.2. Bivariate Analysis of Factors Associated with Fall History, Fear of Falling and Activity Restriction Due to Fear of Falling (Table 2)

As can be seen in **Table 2**, the frequency of fall history, fear of falling and activity restriction was significantly higher among people who had been helped by a third person when filling in the questionnaire. The proportion of people who had fallen in the past year also increased significantly as age increased and was significantly higher among people who lived alone. The frequency of fear of falling and activity restriction increased linearly and significantly as age and the number of falls increased, and was significantly higher among women and people living alone.

3.3. Multivariable Analysis of Influence of Filling in Questionnaire with the Help of a Third Party on Fall History, Fear of Falling and Activity Restriction Due to Fear of Falling (Table 3)

When taking the covariates into account, the frequency of fall history, fear of falling and activity restriction due

Table 1. Distribution of characteristics of the total sample and according to whether the participants filled in the questionnaire on their own or with the help of a third party.

	Total sample		People who filled in the questionnaire on their own		People who filled in the questionnaire with the help of a third party		p**
	n total*	n (%)	n total*	n (%)	n total*	n (%)	
Sex	498		416		82		0.002
Women		302 (60.6)		240 (57.7)		62 (75.6)	
Age (in years)	501		419		82		<0.001
85 and over		49 (9.8)		34 (8.1)		15 (18.3)	
75 - 84		219 (43.7)		170 (40.6)		49 (59.8)	
65 - 74		233 (46.5)		215 (51.3)		18 (22.0)	
Does the person live alone?	497		415		82		0.002
Yes		196 (39.4)		151 (36.4)		45 (54.9)	
Help from a third party to fill in the questionnaire	501		-		-		-
Yes		82 (16.4)		-		-	

*n total = number of valid data for each variable; **p-value of differences in the characteristics of participants according to whether the participants filled in the questionnaire on their own or with the help of a third party. In bold: statistically significant differences.

Table 2. Bivariate analysis of fall history, fear of falling and activity restriction due to fear of falling according to whether the participants filled in the questionnaire on their own or with the help of a third party and according to their characteristics.

	Fall history			Fear of falling			Activity restriction		
	n	Fall(s) within the past 12 months (%)	p-value OR (95% CI)	n	Fear of falling (%)	p-value OR (95% CI)	n	Activity restriction due to fear of falling (%)	p-value OR (95% CI)
Help from a third party to fill in the questionnaire			p = 0.022			p = 0.006			p < 0.001
Yes	82	45.1	1.75 (1.05 - 2.91)	81	75.3	2.11 (1.19 - 3.77)	75	60.0	3.02 (1.77 - 5.19)
No	416	32.0	1	396	59.1	1	380	33.2	1
Sex			p = 0.057			p < 0.001			p < 0.001
Women	301	37.5	1.46 (0.97 - 2.18)	288	70.1	2.37 (1.59 - 3.54)	269	44.6	2.10 (1.38 - 3.21)
Men	195	29.2	1	187	49.7	1	184	27.7	1
Age (in years)			p < 0.001*			p = 0.003*			p < 0.001*
85 and over	49	63.3	4.99 (2.48 - 10.10)	47	74.5	2.39 (1.12 - 5.16)	44	59.1	3.76 (1.83 - 7.79)
75 - 84	219	36.5	1.67 (1.09 - 2.55)	210	66.2	1.60 (1.06 - 2.41)	202	43.1	1.97 (1.28 - 3.04)
65 - 74	230	25.7	1	220	55.0	1	209	27.8	1
Does the person live alone?			p < 0.001			p < 0.001			p < 0.001
Yes	195	45.1	2.21 (1.49 - 3.30)	186	76.3	2.87 (1.87 - 4.41)	179	49.2	2.23 (1.48 - 3.35)
No	299	27.1	1	289	52.9	1	274	30.3	1
Number of falls within the past 12 months			-			p < 0.001*			p < 0.001*
2 and more	-	-	-	97	83.5	4.52 (2.45 - 8.44)	89	65.2	4.63 (2.73 - 7.90)
1	-	-	-	56	73.2	2.44 (1.25 - 4.82)	56	39.3	1.60 (0.85 - 3.01)
0	-	-	-	320	52.8	1	306	28.8	

*Chi-squared for trend. In bold: statistically significant differences.

Table 3. Multivariable analysis of influence of filling in questionnaire with the help of a third party on fall history, fear of falling and activity restriction due to fear of falling.

	Fall(s) within the past 12 months (n = 493) (n fall history = 169)	Fear of falling (n = 470) (n fear of falling = 291)	Activity restriction due to fear of falling (n = 448) (n activity restriction = 168)
	Adjusted OR* (95% CI)	Adjusted OR** (95% CI)	Adjusted OR** (95% CI)
Help from a third party to fill in the questionnaire			
Yes	1.36 (0.81 - 2.30)	1.42 (0.79 - 2.55)	2.22 (1.28 - 3.86)
No	1	1	1
p-value	0.244	0.249	0.005

*OR adjusted for sex, age, living alone and the interaction age * living alone; **OR adjusted for sex, age, living alone and the number of falls; In bold: statistically significant difference.

to fear of falling was significantly higher among people who stated that they had been helped by a third person when filling in the questionnaire. However, this difference was only significant for activity restriction due to fear of falling.

4. Discussion

In our study, a third of respondents reported fall history in the past year. This is comparable to the data in the literature [20]. However, certain studies reported slightly lower figures [33] [34], of which the Enquête Belge de Santé par Interview of 2008 [34] even though it included institutionalised older people and a higher proportion of people aged 85 years and older. It was however carried out in different regions of Belgium, including big cities, and it used a different method to collect data [34]. Fear of falling affected 61.8% of respondents. This is close to the results of other authors [23] [25] [28] [35], of which those by Delbaere *et al.* concerned Belgian data [35]. This is however higher than other results [24] [26] [27] [36]. Activity restriction affected a little over a third of respondents, which is comparable to the data of Zijlstra *et al.* [28], Howland *et al.* [23] and Fletcher and Hirdes [37], even if these have slightly higher figures.

The aim of our article was to study the influence of being helped by a third party when filling in a questionnaire on the reported frequency of falls, fear of falling and related activities restriction. Activity restriction due to fear of falling remained significantly more frequent among respondents who had been helped by a third person after having taken covariates into account, which were, with the exclusion of sex for fall history, each associated with the three outcomes studied. As such, whether or not a respondent was helped when filling in a questionnaire is an important factor to be aware of, since this can influence the frequency of certain aspects related to falls. However, even if we adjusted for sex and age, we cannot exclude that the persons who received help reported more activities restriction since they presented more physical problems for instance. Although we did not study the concordance between participants and proxies, our results point nevertheless in the same direction as the data in the study by Higashi *et al.* [15], in which proxies were more concerned about falls than the older people themselves were. It should be mentioned that in this study, the proxies were asked what they worried about and not what they thought the patients were worried about, in relation to different situations, including falls, based on the activities in the Falls Efficacy Scale [15]. The results of Foran *et al.* [30] differ. They effectively observed that for fall history, fear of falling and activity restriction, there was a substantial to near-perfect, or even perfect agreement between data provided by adults presenting with intellectual disabilities and their “key-caregiver” [30]. However, this study involved a sample of 21 people with an average age of 53 years [30], which is younger than the people involved in our study.

An interesting result is that the influence of being helped when filling in the questionnaire differed for the three events studied, events that could be graded according to how objective and observable they are. Falls would be more objective events, more concrete than the more subjective fear of falling and even more so than activity restriction due to fear of falling. The latter may be the most difficult to assess by outside people who must make a connection between a feeling, fear of falling, and an event, activity reduction, without being able to be certain that this restriction is not linked to something other than this fear. Our results may then point in the

direction of the data in the literature, which shows that the agreement is in general stronger when the health or functional areas considered are “observable” and “likely to be known” by the proxies [7], and when the concepts evaluated are less subjective [3]. For example, although certain activities like “managing money” can be subject to interpretation, others like “walking unaided” cannot be understood in different ways and are associated with better agreement [11]. It should be noted that it is documented that older people do not always report when they have fallen [38] and that they may be reluctant to talk about their fears about falling [25]. However, one might believe that fall history may be more difficult to not mention than fear of falling or activity restriction due to fear of falling, especially when the falls have caused physical repercussions, for example.

Our study and the way we have examined the issue being discussed have certain limitations. The only data available to use was that the person stated that they had received help when answering the questionnaire. It should be noted that this was not a dichotomous question that all respondents had to answer; it was a box to be ticked only if assistance had been received. In addition, we do not know whether this assistance consisted of filling in the questionnaire in place of the person, helping them understand questions and/or writing the responses, or whether the assistance was necessary for all items in the questionnaire or only for specific ones. As such, it is possible that people who reported having helped did not meet the exact definition of being proxies [3]. It should however be emphasized that it seems that proxies may have influenced the responses given by the person they were helping, even if they were not responding in their place [5]. Their influence could have already had an effect when reading the questions, translating them or writing the responses [5]. This aspect is important to keep in mind when studying older people. Moreover, we did not have access to coupled data from older persons and their proxies, which would have allowed us to compare the data provided and evaluate for example the agreement or the biases. We also did not have external gold-standard data, such as medical records, with which we could have compared the data collected. In addition, the number of people who received help in our study was small, which may limit the strength of our study and the conclusions that can be drawn. Finally, we had no information about the characteristics of the people who had helped, or their relationship to the person, and we only have a small amount of information about the characteristics of the people included in the survey. Related to this, it should be noted that the literature reports that other factors may be related, among older people, to falls [39] [40], fear of falling and activity restriction due to fear of falling [41]. Inclusion of these additional factors in subsequent studies may be worthwhile. In addition, the agreement and the observed biases (*i.e.* the proxies over- or under-reporting certain issues or disabilities [7]) appear to be influenced by other factors, separate from the areas investigated and the specific items investigated. Among others, the influence of certain characteristics of the people concerned (age [14] [42]—sex [42] [43]—functional status [14]—presence of symptoms of depression [7] [11] [44] or cognitive impairment [7] [11] [13] [42] [45]) and of certain characteristics of the proxies’ (age [7] [10] [11] [16]—sex [7] [11] [16] [42] [43]—ethnic origin [8]—whether they are “lay” people or health-care professionals [9] [18]) has been documented. The type of relationship connecting the proxies to the people concerned (child or spouse for example) also plays a role [7] [11] [16] [44] as does whether they live with the person concerned [7] [10] [11] [15] [16] or whether they have frequent [15] [16] [42] or close [12] contact with them. Related to this however, it should be noted that the burden that may be felt by the proxies in relation to the help or care they provide to the person concerned may negatively impact the agreement [8] [11] [12]. Another factor that may also have an influence is the desire of the proxies to highlight the disabilities of the person in order for them to receive the necessary support [12]. Finally, other factors, not examined in our study, may influence the agreement and the biases, including the type of questionnaire [9], the formulation of the questions [4],... Further studies should consider these different elements in the future.

5. Conclusion

Our results show, despite their limitations, that when conducting surveys among older people relating to falls, and more generally, it is important to know whether they received help when filling in a questionnaire. This can be associated with a higher reported frequency of certain events, even after taking into account the effect of other covariates for the activity restriction. Given the current and future ageing of our populations and taking into account the limitations of our study and the recommendations in the literature, more detailed exploration of the influence of proxies may be warranted on the information provided relating to falls, for instance through the collection of more information on the characteristics of the person concerned, the characteristics of the proxy [8] [14], the relationship between them and the older person [12] and the burden that may be felt by the proxy. In

addition, as is recommended, it would be appropriate, where possible, to formulate the questions around clearly, well-defined activities [11] (for example for the activity restriction due to fear of falling), or concrete, observable events [11] [12], rather than around assessments [11], such as asking a proxy whether the person concerned had already told them that they were afraid of falling or had restricted certain activities, or whether they had already witnessed falls. Finally, it would be useful to limit the number of options and response categories [11] [12] and to collect external gold-standard reference data [7] [8], based on medical records for fall history, for example.

Conflict of Interests

The authors declare that there is no conflict of interests regarding the publication of this article.

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