

The availability of care among frail older adults: impacts on care management in a crisis context — the Fibra Study

Disponibilidade de cuidado em pessoas idosas frágeis: impactos na gestão do cuidado em um contexto de crise — Estudo Fibra

Juliana Lustosa Torres¹ , Lygia Paccini Lustosa² 

¹Universidade Federal de Minas Gerais, Preventive and Social Medicine Department – Belo Horizonte, MG, Brazil.

²Universidade Federal de Minas Gerais, Physical Therapy Department – Belo Horizonte (MG), Brazil.

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Abstract

Background: In Brazil, most of the care provided is informal, but its availability remains relatively little explored in the context of frailty. **Objective:** The objective of this study was to describe the availability of care among older adults from Belo Horizonte, Brazil, and its association with frailty. **Method:** This is a cross-sectional study based on 598 older adults from the Fibra-BH Study (2008/09). Frailty was defined using the 5-item of physical frailty phenotype. The availability of care included subjective and objective measures. Adjusting variables were age, sex, education, and self-rated health. Statistical analyses were based on a Poisson regression model with a robust error variance. **Results:** The prevalence of frailty was 11.4% and pre-frailty was 56.4%. The availability of care was slightly lower among frail than pre-frail and non-frail, where 17% lived alone, 14% had nobody to rely on, and 13% were childless. An association was observed between a lack of availability of care and frailty only among men, regarding living alone and having nobody to rely on. **Conclusion:** Only a small part of older adults have a lack of availability of care, but it is slightly higher among frail older adults. Focus on male older adults with a lack of availability of care is necessary due to a higher probability of having frailty or pre-frailty.

Keywords: frailty; long-term care; social environment; social support.

Resumo

Introdução: No Brasil, a maioria do cuidado prestado é informal, mas a sua disponibilidade permanece pouco explorada no contexto da fragilidade. **Objetivo:** Descrever a disponibilidade de cuidado em idosos frágeis de Belo Horizonte (Minas Gerais) e verificar se isso é associado à fragilidade. **Método:** Trata-se de um estudo transversal, baseado em 598 idosos participantes do estudo Fibra – Belo Horizonte (2008/2009). A fragilidade foi definida por meio de cinco itens do fenótipo da fragilidade física. A disponibilidade de cuidado incluiu medidas objetivas e subjetivas. As variáveis de ajuste foram idade, sexo, escolaridade e autoavaliação da saúde. A análise estatística foi baseada no modelo de regressão de Poisson com variância robusta. **Resultados:** A prevalência de fragilidade foi de 11,4% e da pré-fragilidade foi de 56,4%. A disponibilidade de cuidado foi um pouco menor entre os frágeis do que em relação aos pré-frágeis e não frágeis, dos quais 17% moravam sozinhos, 14% não tinham ninguém para cuidar e 13% não tinham filhos. Foi observada uma associação entre a falta de disponibilidade de cuidado e a fragilidade, apenas entre os homens, em relação a morar sozinho e a não ter ninguém com quem contar. **Conclusão:** Somente uma pequena parte dos idosos apresentam falta de disponibilidade de cuidado, que é um pouco maior entre os frágeis. Faz-se necessário um foco nos homens com ausência de disponibilidade de cuidado devido à maior probabilidade de apresentar fragilidade ou pré-fragilidade.

Palavras-chave: fragilidade; assistência de longa duração; meio social; apoio social.



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Correspondence: Juliana Lustosa Torres. E-mail: jlt.fisioufmg@hotmail.com

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INTRODUCTION

Considering the population aging, the burden of frailty has become a challenge for both public health systems and family care since it is one of the major conditions associated with aging¹. In case of middle-income countries, such as Brazil, this phenomenon demands even more attention because of the steep growth of older adults in the last and further decades².

Frailty is a multidimensional syndrome that involves the interaction of biological, psychological, and social factors³. There is a lack of consensus in the literature regarding the practical measure of frailty in clinical settings, showing numerous scales based on different conceptual definitions⁴. However, there is a widespread performance-based phenotype³ that may be useful in clinical settings⁵. It comprises five positive phenotypic criteria:

- unintentional weight loss, measured by self-report of losing more than 10 pounds in the last year;
- self-reported exhaustion, answering moderate or most of the time for the following two items of the CES-D Depression Scale: the feeling that everything they did was an effort, and that they could not get going;
- weakness, measured by grip strength using cutoffs according to sex and body mass index;
- slowness, measured by walking speed using cutoffs according to sex and height;
- low physical activity, originally measured using the short version of the Minnesota Leisure Time Activity questionnaire³.

The prevalence and incidence of frailty and pre-frailty vary across countries' incomes (higher in middle-income countries) and types of frailty definitions⁶. The literature reports that the prevalence of frailty ranges from 3.9% in China to 51.4% in Cuba⁴. In Brazil, according to a recently published meta-analysis, it varies from 8 to 47%⁷. Additionally, a representative population-based study of older Brazilian adults found a prevalence of 13.5% (95% confidence interval [CI] 11.9–15.3) among older adults aged 60 years and over, and 16.2% (95%CI 14.3–18.3) among those aged 65 years and over⁸.

Regardless of its operational definition, it is well known that frailty is associated with a higher risk of adverse outcomes such as physical disability and long-term care⁹. Both frailty and pre-frailty were statistically at higher risk of needing long-term care¹⁰. This increased demand will have multiple implications for individuals, families, health systems, and the larger society. One of the main implications is the higher healthcare costs (increasing by nearly 54%) particularly observed in the inpatient sector and informal nursing care¹¹. Recently, this scenario has become even worse considering the current Brazilian economic crisis where the Gross Domestic Product (GDP) has been decreasing since 2011¹², and the lack of priority given to the Unified Health System (in Portuguese *Sistema Único de Saúde*), reinforced by Constitutional Amendment No. 95 (EC-95/2016), which freezes the public budget for 20 years¹³.

In Brazil, patients often remain with their family, with some source of support from civil and/or religious communities rather than going to long-stay institutions (nursing homes)¹⁴. Most of the care (68.5%¹⁵) is provided by the nuclear family, which is considered an important and cheapest (i.e., normally unpaid) source of informal care. However, considering that nowadays older adults are significantly less likely to have a spouse or a grown child living nearby (smaller nuclear family network)¹⁶, the availability of informal care remains relatively little explored in the context of frailty. For example, in the United States, unmarried frail older adults without children are about 31% less likely to receive unpaid help from family and friends than those with two or more adult children¹⁷. In China, childless individuals whose children have all died exhibit worse self-rated health than individuals with children¹⁸. However, another study in Belgium showed that only 15.8% of high frail older adults in need of assistance do not receive help¹⁵. Qualitatively, the geographical accessibility, the lack of having someone around, and the absence of trust in care providers have been reported as barriers to care access¹⁹.

There are two types of measuring the availability of informal care: objective, considering the number of people available for taking care in case of need (number of children, number

of people living with), and subjective, including the expectation of support for care, related to the belief that close individuals will provide the necessary support in case of need²⁰. A Brazilian study has demonstrated that subjective measures of support, as well as objective measures, are sensitive predictors of functioning²¹. Therefore, this study aimed to describe the availability of care among older adults and its association with frailty. We believe that older adults with a smaller nuclear family network are more likely to have worse health indicators regarding frailty.

METHODS

Data source and sampling

This is a descriptive cross-sectional analysis based on the Frailty in Brazilian Older People (in Portuguese, Fraigilidade em idosos brasileiros [Fibra]) Study's participants living in Belo Horizonte, from Universidade Federal de Minas Gerais pole. The Fibra Study is a multicenter network conducted in several Brazilian municipalities, including Belo Horizonte-MG (Fibra-BH). The Fibra-BH sample size was calculated to reach 50% of determined characteristics, according to the population total number of the municipality (i.e., higher than 1 million). It was a two-stage cluster sample design where the census enumeration areas of the Brazilian Institute of Geography and Statistics were randomly selected and regarding the older adult population size in the selected census enumeration areas, we set the minimum interviews in both census enumeration areas and localities. Details of sampling design are available elsewhere²².

The inclusion criteria of the Fibra-BH study included being 65 years old and over, being community-dwelling, and having Mini-Mental State Examination²³ score higher than 17 (i.e., without cognitive impairment). Participants were excluded if they had any stroke, had Parkinson's disease, were using a wheelchair, and were bedridden²⁴. Data were collected in 2008/2009 by interviewers trained previously. For the current analyses, we included only older adults with complete information on the studying variables.

All participants signed informed consent. The Fibra-BH was approved by the Federal University Ethics Committee (ethic no. 187/07).

Measures

The dependent variable was frailty. The definition of frailty was made using the frailty phenotype proposed by Fried et al.³, comprising five positive phenotypic criteria (unintentional weight loss, self-reported exhaustion, weakness, slowness, and low physical activity). Accordingly, community-dwelling older adults were classified as frail (three or more criteria), pre-frail (one or two criteria), and non-frail (no criterion). For statistical purposes, taking into account that both frailty and pre-frailty were statistically at higher risk of needing long-term care¹⁰, we combined the frail and pre-frail groups and compared with the non-frail group.

The target determinants of frailty were the availability of care. We used three measures to assess the availability of care:

- living arrangement (living alone, living with a partner or children, and other arrangements, including living with a caregiver or friends or other family members);
- expectation for care, assessed by having nobody to rely on when in need (yes/no);
- number of children alive, including those living outside the household (continuous).

We used sociodemographic and health characteristics as adjusting variables. Sociodemographic characteristics included age, sex, and complete years of education. Health characteristics included self-rated health, a simple measure that predicts mortality similar to objective measures²⁵, dichotomized into very good/good and fair/bad/very bad. We categorized years of education into three categories: <4 years, 4–8 years, and ≥9 years.

Statistical methods

These descriptive analyses were based on different statistical methods: first, we used Pearson's χ^2 test with Rao-Scott correction and t-test, according to the sort of variable (categorical or continuous, respectively), to set a crude descriptive analysis, and second, we implemented the Poisson regression model with a robust error variance to estimate prevalence ratios (PR) and their 95% CIs, adjusted by sociodemographic characteristics and self-rated health. Adjusted models were performed separately for every variable of the availability of care and stratified by sex. All analyses were performed using STATA 13.0 (Stata Corp LLP, College Station, TX), considering the sampling parameters (individual weight and household clustering of individuals).

RESULTS

Of the 606 Fibra-BH study participants living in Belo Horizonte, 598 (98.7%) had complete information about the studying variables and were included in the current analysis. The characteristics of the study population by frailty/pre-frailty classification are shown in Table 1. The mean age of the participants was 74.3 years (SD=6.4), with females being the majority (66.5%). The prevalence of frailty was 11.4% and pre-frailty was 56.4%, with a total prevalence of 67.8%. The availability of care was statistically similar among frail/pre-frail and non-frail older adults, but slightly lower among frail/pre-frail: 16.1% of frail/pre-frail older adults have been living alone, and 9% have nobody to rely on and presented a mean number of children of 4 (SD=2.8).

Table 1. Descriptive analysis of the participants according to frailty/pre-frailty status – **Frailty in Brazilian Older People (Fibra) Study, Belo Horizonte-MG (2008–2009).**

| Variables | Total | Frailty/pre-frailty | | p-value |
|-----------------------------------|------------|---------------------|------------|---------------------|
| | | No | Yes | |
| Female sex, (%) | 66.5 | 20.4 | 46.0 | 0.397 ^a |
| Age, mean (SD) | 74.3 (6.4) | 72.2 (5.5) | 75.3 (6.6) | <0.001 ^b |
| Years of education, (%) | | | | 0.012 ^a |
| <4 | 27.8 | 6.7 | 21.1 | |
| 4–8 | 46.8 | 14.6 | 32.2 | |
| 9+ | 25.4 | 10.9 | 14.5 | |
| Self-rated health, (%) | | | | <0.001 ^a |
| Very good/good | 61.3 | 78.5 | 53.1 | |
| Fair/bad/very bad | 38.7 | 21.5 | 46.9 | |
| Number of children, mean (SD) | 3.9 (2.7) | 3.9 (2.6) | 4.0 (2.8) | 0.723 ^b |
| Living arrangement, (%) | | | | 0.539 ^a |
| Living alone | 14.7 | 11.9 | 16.1 | |
| Living with a partner or children | 40.7 | 42.0 | 40.2 | |
| Other arrangements | 44.6 | 46.2 | 43.8 | |
| Expectation for care, (%) | | | | 0.059 ^a |
| Somebody to rely on | 88.7 | 97.6 | 91.0 | |
| Nobody to rely on | 11.3 | 2.4 | 9.0 | |
| Total (N)^c | 598 | 182 | 416 | |

^aBased on Pearson's χ^2 test with Rao-Scott correction; ^bBased on the t-test; Note: estimated percentages, considering the sampling parameters; ^cTotal sample without sampling parameters.

Figure 1 shows the lack of availability of care according to the frailty status. Only a small percentage of older adults (nearly 12%) showed a lack of availability of care. However, frail and pre-frail older adults showed a slightly higher lack of availability of care compared to non-frail, regarding nobody to rely on (around 14% vs. 9%), living alone (14 and 17% vs. 10%, respectively), and childless (around 13% vs. 9%). Among frail individuals, the lack of availability of care is higher regarding living alone, where 17% have been living alone. However, none of these differences were statistically significant.

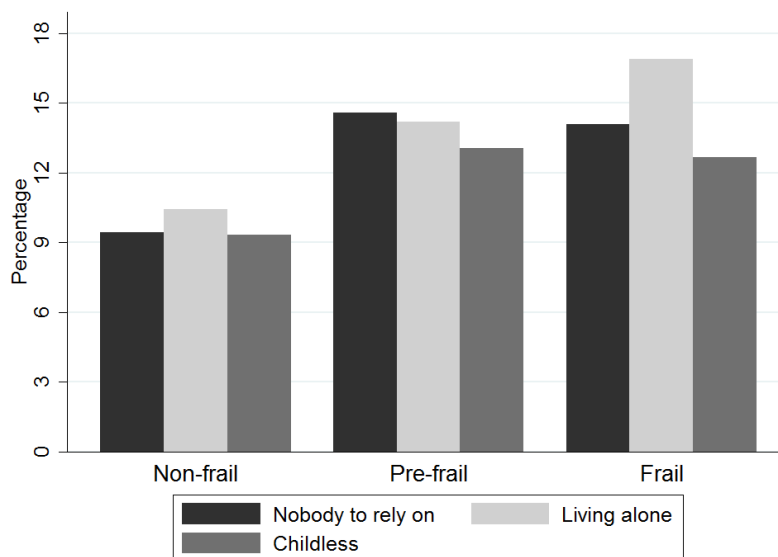


Figure 1. Percentage of older adults with a lack of availability of care according to the frailty status — Frailty in Brazilian Older People (Fibra) Study, Belo Horizonte-MG, n=598 (2008–2009).

Table 2 shows the adjusted prevalence and PR of the multivariate association between frailty/pre-frailty and the availability of care overall and for men and women separately. Taking all these into consideration, we did not observe any association between frailty/pre-frailty and the availability of care. However, even after adjustments, the expected probability of frailty/pre-frailty was slightly higher among those living alone (72%) and those with nobody to rely on (74.3%). After the stratification by sex, the results showed an association only among men. The predicted probability of frailty/pre-frailty was statistically higher among men living alone (89.5%) and those having nobody to rely on (78.2%). Additionally, a lower prevalence of frailty/pre-frailty for those living with a partner or children (PR=0.65; 95%CI 0.49–0.86) and for other living arrangements (PR=0.72; 95%CI 0.55–0.96) compared to those living alone, and a positive association between nobody to rely on and frailty/pre-frailty were found (PR=1.24; 95%CI 1.01–1.52). No association was found among women. However, the predicted probability of frailty/pre-frailty was slightly higher among women with nobody to rely on (73.2%) compared to those with somebody to rely on (68.4%).

DISCUSSION

According to the current study, only a small percentage of older adults showed a lack of availability of care. However, the pre-frail and frail older adults showed a slightly higher lack of availability of care compared to non-frail. Considering frail older adults, the higher percentage of lack of availability of care is the older adults living alone. Our multivariate model showed that having nobody to rely on when they are in need and the living arrangement were associated with frailty/pre-frailty only among men. Those living with a partner or children and other living arrangements rather than living alone showed a lower prevalence of frailty/pre-frailty. Moreover, we found a prevalence of frailty of 11.4%, similar to other studies conducted in Brazil^{4,7,8,22}.

Table 2. Expected probability of frailty/pre-frailty and prevalence ratios of the multivariate association between frailty/pre-frailty and the availability of care in 598 older adults – Frailty in Brazilian Older People (Fibra) Study, Belo Horizonte-MG (2008–2009).

| Variables | Overall (men and women) | | | Men | | | Women | | |
|-----------------------------------|--|---------------------|--|---------------------|--|---------------------|--|---------------------|-----------|
| | Expected probability of frailty/pre-frailty ¹ (%) | Frailty/pre-frailty | Expected probability of frailty/pre-frailty ² (%) | Frailty/pre-frailty | Expected probability of frailty/pre-frailty ² (%) | Frailty/pre-frailty | Expected probability of frailty/pre-frailty ² (%) | Frailty/pre-frailty | |
| Overall | | PR | 95%CI | | PR | 95%CI | | PR | 95%CI |
| Number of children | 71.2 (childless) | 0.99 | 0.97–1.01 | 68.4 (childless) | 0.99 | 0.94–1.04 | 72.2 (childless) | 0.99 | 0.96–1.01 |
| <i>Living arrangement</i> | | | | | | | | | |
| Living alone | 72.0 | 1.00 | | 89.5 | 1.00 | | 69.9 | 1.00 | |
| Living with a partner or children | 67.8 | 0.93 | 0.77–1.20 | 58.3 | 0.65 | 0.49–0.86* | 72.6 | 1.04 | 0.83–1.31 |
| Other arrangements | 67.1 | 0.93 | 0.77–1.13 | 64.9 | 0.72 | 0.55–0.96* | 65.9 | 0.94 | 0.74–1.19 |
| <i>Expectation for care</i> | | | | | | | | | |
| Somebody to rely on | 66.8 | 1.00 | | 63.3 | 1.00 | | 68.4 | 1.00 | |
| Nobody to rely on | 74.3 | 1.11 | 0.98–1.29 | 78.2 | 1.24 | 1.01–1.52* | 73.2 | 1.07 | 0.88–1.30 |

95%CI: 95% confidence intervals; PR: prevalence ratio; ¹Adjusting for age, sex, years of education, and self-rated health; ²Adjusting for age, years of education, and self-rated health, stratifying by sex for men and women; *p<0.05.

Frailty and pre-frailty are conditions that demand long-term care¹⁰, and our results show that these categories have a higher lack of availability of care. In the current analyses, we considered the availability of care instead of the care effectively provided. In a convenience sample of older adults in Montes Claros, Minas Gerais, the authors found that most of the frailty older adults (70.7%) had a caregiver. Indeed, the definition of frailty was made differently based on the nine domains of the Edmonton Frail Scale²⁶. However, our groups fit older adults at risk of having a limited source of care and need special attention from health professionals.

When we stratified by sex, we found a slightly higher but not significant probability of having frailty/pre-frailty among men having nobody to rely on compared to women (78.2 and 73.2%, respectively), showing an association with frailty/pre-frailty only among men (PR=1.24; 95%CI 1.01–1.52). Indeed, it has been noted that people in need of support or care, such as frail individuals, are often those least likely to receive support²⁷ and medical care as they thought they needed²⁸. Moreover, literature shows that men report lower levels of social support compared to women²⁹, probably because men's social support is heavily focused on their spouses, whereas women are much more likely to rely on a child, close relative, or a friend^{27–29}. Regardless of the reason to perceive having nobody to rely on, we also found a slightly higher probability of having frailty/pre-frailty among men living alone than women living alone (89.5 and 69.9%, respectively).

Regardless of women showing a statistically nonsignificant high prevalence of frailty compared to men (46 and 21.9%, respectively), men with a lack of informal care availability are more likely to have frailty and demand special attention from the healthcare system. Some of the reasons are in contrast to women, men are less concerned with their health and use health system less frequently³⁰, leading to diagnosis at severe states. Regarding care, they would need to hire a formal caregiver or to be institutionalized, leading to an increase in the budget they spend on healthcare. In Brazil, on average, a family spends R\$179.01 on healthcare³¹, and older adults' expenditure on medicine represents 23% of their income³⁰. Government programs that provide care are limited nowadays due to EC-95/2016, such as the "Melhorem Casa Program," the Primary Care Strategy³², and the "Formação de cuidadores de idosos National Program³³,"

that make employees qualify for adult care support.. Nevertheless, most of the older Brazilian adults do not receive formal care but informal care. For example, according to the National Health Survey 2013, 5.7% of older adults needing help did not receive any help, and 81.8% received informal help³⁴. Yet, most older adults received help from an unpaid family member resident in the same household (62%)³⁴, heavily concentrated among women³⁵. Therefore, knowing the informal available caregivers and that women are more likely to provide care rather than men is necessary for implementing health education strategies and routine supervision, mainly at primary healthcare.

One Brazilian study conducted in a social vulnerability area of São Carlos, São Paulo, showed that 60% of the older adults' formal or informal caregivers aged ≥ 60 years were classified as frail/pre-frail³⁵ or at risk of frailty³⁶, similar to the international data showing that they are more likely to be pre-frail³⁷. Yet, we have to consider that frailty is associated with caregiver burden³⁸. Additionally, caregivers from high social vulnerability areas had lower education levels and received less emotional and material help to care³⁹. Despite being frail themselves, around 20% of frail adults provided unpaid caregiver support to a frail older adult²⁸. These data show that in some situations, even when the source of care is available, the provided care might be limited due to caregiver conditions. It highlights the necessity of supervising those older adults and caregivers continuously by the primary care team. However, with limited health funding, primary care access might not be universal and might not ensure access to frail older adults. In 2018, some primary care teams were dismissed by governments in some Brazilian states, such as the 239 primary care teams in Rio de Janeiro city, RJ. Then, the primary care range of actions was shortened.

Our study has some limitations. First, our study has a cross-sectional design, which impedes pointing out the causal chain. Second, our sample is based on data from only one large city in Brazil, limiting the generalization to other Brazilian cities. Despite these limitations, our study has a strength methodology by using a selected sample derived from a large municipality in Brazil and having a protocol rigor, ensuring its internal validity.

CONCLUSION

The burden of frailty has become a challenge for public health systems because of its demands on long-term care. Only a small part of older adults have a lack of availability of care, but it is slightly higher among frail older adults. Public programs targeting this population are necessary to provide adequate care support. Focus on male older adults with a lack of availability of care should be due to a higher probability of having frailty/pre-frailty.

AUTHORS' CONTRIBUTIONS

JLT: Conceptualization, Data curation, Formal Analysis, Methodology, Writing – original draft, Writing – review & editing. LPL: Formal Analysis, Methodology, Supervision, Writing – original draft, Writing – review & editing.

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