RESEARCH

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Lack of anticipated support for care for community-dwelling older adults

Ausência de expectativa de suporte para o cuidado aos idosos da comunidade

Falta de expectativas de ayuda para el cuidado de adultos mayores residentes en la comunidad

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ABSTRACT

Objective: to identify the factors associated with lack of anticipated support for care for community-dwelling older adults. **Method:** this study presents comparison and logistic regression analyses of data from 671 individuals who took part of the multicentric study entitled "Frailty in older Brazilians" - a quantitative, epidemiologic and transversal investigation carried out between 2008 and 2009. **Results:** the subjective evaluation of anticipated support for care for community-dwelling older adults was a good indicator of risk for lack of anticipated support for care in women, older adults who live alone and those with poor self-rated health. **Conclusion:** it is necessary to reflect upon the formal support system currently available for older people in Brazil, considering that those who most frequently presented lack of anticipated support for care are an increasing population. The study also highlights the importance of using subjective methods for the evaluation of the adequacy of older adults' support network.

Descriptors: Older adults; Geriatric Nursing; Social Support; Health Care; Ageing.

RESUMO

Objetivo: identificar fatores associados à ausência de expectativa de suporte para o cuidado aos idosos da comunidade. **Método:** foram utilizados parte dos dados do estudo multicêntrico "Fragilidade em Idosos Brasileiros", pesquisa quantitativa, epidemiológica e transversal desenvolvida no período de 2008 a 2009. Foram realizadas análises de comparação e regressão dos dados de 671 idosos. **Resultados:** a avaliação da expectativa de suporte para o cuidado aos idosos mostrou-se um bom indicador de risco para ausência de expectativa de suporte em mulheres, idosos que residiam sozinhos e com percepção ruim da própria saúde. **Conclusão:** conclui-se que é preciso refletir sobre o sistema de suporte oferecido aos idosos no Brasil, visto que o perfil destes que estão em risco é cada vez maior na população. Ressalta-se também a importância da inserção de métodos subjetivos para avaliação da percepção dos idosos sobre suporte para o cuidado.

Descritores: Idoso; Enfermagem Geriátrica; Apoio Social; Atenção à Saúde; Envelhecimento.

RESUMEN

Objetivo: identificar los factores asociados a la falta de expectativas de ayuda para el cuidado de adultos mayores residentes en la comunidad. **Método:** este estudio presenta un análisis de comparación y regresión logística de 671 individuos que tomaron parte del estudio multicentro titulado "Fragilidad en ancianos brasileños" - una investigación cuantitativa, epidemiológica y transversal llevada a cabo entre 2008 y 2009. **Resultados:** la evaluación subjetiva de expectativas de ayuda para el cuidado de adultos mayores residentes en la comunidad ha sido un buen indicador de riesgo para la falta de

expectativas de ayuda para el cuidado en mujeres, adultos mayores que viven solas y aquellos con una mala auto percepción de su salud. **Conclusión:** es necesario reflexionar sobre el sistema de apoyo formal que actualmente existe disponible para las personas mayores en Brasil, considerando que aquellos que presentan más frecuentemente una falta de expectativas de ayuda son una población creciente. El estudio señala además la importancia de usar métodos subjetivos para la calidad de la red de apoyo adecuada para adultos mayores.
Descriptores: Adultos mayores; enfermería geriátrica; apoyo social; cuidado de salud; envejecimiento.

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INTRODUCTION

The social support offered to older adults has been considered a protective factor of the physical and mental health of this population, as well as it has been associated with lower levels of mortality rates in this particular age group[1-2]. Social support promotes physical and mental health, helping older adults to cope with chronic or acute diseases, as well as with physical or social vulnerability[3]. In addition, research demonstrates that social support promotes functional capacity and helps older adults to cope with stressful situations, confirming the importance of social and affective relations for an active ageing[1]. Despite these benefits, the informal social support provided for by family members, friends, acquaintances, and voluntary community services is often the only source of support available for the majority of the older population in Brazil, as the public sector often does not provide an adequate network of social support to these individuals[4-5].

Studies have demonstrated that subjective measures of social support, such as perceived support or expectation of support for care, are more sensitive predictors of physical and mental health than objective measures[6-7], meaning that the perception of such support is likely to be more important than its mere availability. Among the different methods for the subjective evaluation of social support available in the literature, expectation of support for care can be defined as the person's belief that close individuals will provide to him/her the necessary support in case it is needed[8].

Research has shown that the expectation of support for care is a psychological mechanism that helps older people to cope independently with their daily challenges. Being able to successfully manage a difficult situation without direct intervention from other people, but believing that support will be available in case it is needed, promotes self-efficacy and well-being[9]. Moreover, expectation of support for care can reduce anxiety and depression symptoms[10], promotes faster recovery from diseases[11] and has been associated with lower levels of mortality in older people[12].

Therefore, identifying older individuals with lack of anticipated support for care may help to detect those who are in higher risk for stress, loneliness, poorer mental and physical health, as well as higher risks for morbidity and mortality. Considering that the older Brazilian population is increasing and that the majority of these people is currently living without adequate formal social support or in a vulnerable situation — impacting on women, families and available public services —, research investigating their subjective views about the available support and factors associated with the lack of anticipated support for care is paramount.

Despite its relevance, there are still few international studies investigating the anticipated support for care for older adults and none national study about this topic is available to date, except for the preliminary results of this current investigation published elsewhere[13]. Hence, this current research is of great relevance and aims to identify the variables associated with the lack of anticipated support for care for community-dwelling older adults in Brazil. The results hereafter presented will allow the identification of those community-dwelling individuals who may be in higher risk for lack of anticipated support, which will help nurses to anticipate the care needs of those who may be at a higher risk of lack of support. Furthermore, results from this data analysis will allow a reflection upon the formal support system available in Campinas-SP.

METHOD

This study is part of a larger multicenter study focused on the health and well-being of older adults (≥65 years old), entitled "Frailty in Brazilian Elderly Individuals" (the FIBRA Study). Both the FIBRA study and the current investigation were approved by the Ethics Committee of the Faculty of Medicine, State University of Campinas, SP, Brazil. Recruitment took place at the older adults' own homes. Those who accepted to participate were referred to a single session of data collection taking place in a public and of easy access environment. All participants signed a consent form written in accordance with the National Ethics and Research Council in Brazil.

The FIBRA study enrolled around 8,000 older adults living at the urban areas of 17 cities located from north to south areas of Brazil. A probabilistic sampling technique was utilised and data collection took place from September 2008 to June 2009. Inclusion criteria were: to be aged 65 years old or above, to be able to understand instructions about the study, to be permanently living at the study area, and to provide consent. For the current sub-study, an additional inclusion criterion was having answered the

variables of interest. Individuals were excluded if he or she: presented advanced cognitive impairment, memory loss, problems with attention, time and special orientation or communication issues; were wheelchair users; were temporarily or indefinitely bedridden; had major sequels of stroke, with loss of local strength and/or aphasia; were victims of Parkinson's disease in advanced or unstable stages, or had major problems with motility, speech or affectivity; had major problems with hearing or vision which could strongly compromised communication; and those individuals at the end of life.

FIBRA study enrolled 835 older adults. The current study presents data from 671 participants who answered all the variables under investigation. After signing the consent form, participants were introduced to the study protocol[14], which contained sociodemographic questions, the mini mental state examination (MMSE), blood pressure and anthropometric measures, collection of blood samples, buccal cavity examination, and frailty measures[15] — grip strength, walking speed, levels of physical activity, self-reported exhaustion, and weight loss. Individuals performing above the MMSE threshold participated in further measurements, following a second study protocol.

Variables of interest were investigated according to the following conditions[14].

Sociodemographic variables

- Gender: obtained from self-report (female/male).
- Age group: obtained from self-report (in years) and registered as a continuous variable. It was after grouped: 1) 65-74; 2) ≥75.
- Living arrangements: it was investigated using the question: "Who lives with you?", followed by the options (yes or no for each of them): alone; with my spouse/partner; with child; with grandchild; with great grandchild; with other relative (s); or with members outside family. For the current study, answers were categorized in two groups: "alone" and "not alone".
- Anticipated support for care to perform Basic Activities of Daily Living (BADL) or Instrumental Activities of Daily Living (IADL): nominal and dichotomic variable. Participants were asked: "If you need help to perform any of these activities, do you have anyone to support you?" (yes/no). If yes, participant was asked about his/her relationship with this person (spouse, child, friend, etc.). In this case, participant could answer to more than one person in the list. Responses were then classified in one, two or more people. Participants who answered "no" to the former question were considered with "lack of anticipated support for care", which is the dependent variable of this study.
- Self-rated health: ordinal variable. Participants were asked: "Overall, how do you rate your current state of health?". There were five possible answers to this item, ranging from "very good" to "very poor".
- Self-reported diseases: dichotomic variable. Participants were questioned whether a doctor had ever diagnosed one or more of the diseases listed. For each disease, participant opted for "yes" or "no". For the current study, this variable was grouped in "none to two, three or more".
- Frailty phenotype: Five variables were investigated:
  1. Not intentional weight loss in the last twelve months: participants were asked whether he/she had not purposively lost weight in the last year. In case of an affirmative answer, he/she was asked about how many kilograms he/she lost.
  2. Exhaustion: evaluated through two scalar and self-reported items. There were four options for each of them: "always", "most of the times", "sometimes", "never or rarely".
  3. Grip strength: measured using a dynamometer Jamar (produced by *Lafayette Instruments, Lafayette*, IN, USA), used in the participants' dominant hand.
  4. Physical activity: obtained via self-report of the weekly frequency and duration of exercises and domestic chores performed in the last seven days, based on the items of the Brazilian version of the Minnesota Leisure Time Activities Questionnaire[16].
  5. Walking speed: obtained via the time (in seconds) that the participant took to walk, in a usual manner for him/her, a distance of 4.6 meters, which was marked on the floor. Participant walked this distance for three times and the length of time taken for each attempt was recorded.

Data was analysed and specific thresholds were calculated for each frailty criterion, as there is no universal established values available for this phenotype.

- Functional independency:
  - Advanced Activities of Daily Living (AADLs): participants were given a list of activities and were asked to choose between "never did", "stopped doing", "still do" for each of items. The current study considered only those participants who had chosen the option "stopped doing".
  - Instrumental Activities of Daily Living (IADLs): participants were asked whether they were totally independent, needed help or were totally dependent of help to perform each of the listed activities. The current study considered those individuals who had chosen "need help" or were "totally dependent of help" for any of the listed activities.
  - Basic Activities of Daily Living (BADLs): participants were asked whether they were totally independent, needed help or were totally dependent of help to perform each of the listed activities. The current study considered those individuals who had chosen "need help" or were "totally dependent of help" for any of the listed activities.

Data analyses included descriptive measures of categorical variables, with absolute frequency (n) and relative

distribution (%). Descripted statistics were calculated for continuous variables, as well as mean, standard deviation, minimum and maximum, and median. In order to identify the factors associated with the lack of anticipated support for care, univariate and multivariate logistic regression with stepwise criterion were calculated. A confidence interval of 95% was used in all statistical tests.

RESULTS

Participants (n = 671) were mostly women (68.70%), aged 75 years old or less (69.15%), living with someone else (83.91%). Participants' age ranged from 65 to 90 years old, with an average of 72.31(± 5.33) and median of 72 years old. The first quartile was around 68 years old and the third quartile around 76 years old. Concerning their health status, 57.10% of participants reported having none, one or two diseases. From this group, around 11% had no disease diagnosed in the past. About half of the sample was classified as being frail or pre-frail (55.14%), and 58.77% rated their own health as being "good" or "very good". The great majority of participants were dependent of help to perform at least one Activity of Daily Living (ADL) (94.10%). From this group, the majority had stopped performing one AADL (92.23%), but kept able to perform IADLs (74.14%) and BADLs (89.47%) independently. The anticipated support for care was positive for the vast majority of participants (89.12%). From this group, 44% expected to receive help from only one person. Results from correlation analysis between anticipated support for care and other investigated variables are outlined in Table 1.

Participants who had positive anticipated support for care were mostly men, those who lived with someone else, those who stopped performing at least one AADL and who had self-rated health good or very good. On the other hand, those with lack of anticipated support for care were mostly those older individuals who evaluated the state of their health as being poor or very poor, and those who lived alone.

Univariate logistic regression demonstrated that those older individuals who rated their current state of health as being poor or very poor had three times more chances of having lack of anticipated support for care. In addition, women had two times more chances of having lack of anticipated support for care. If the older individual lived alone, odd ratio was three times higher than those who lived accompanied (Table 2).

The multivariate logistic regression confirmed the previous analyses. It showed that the risk for lack of anticipated support for care is three times higher in older adults who live alone and almost four times higher in those with poor or very poor self-rated health (Table 3).

A multivariate logistic regression controlled by gender and age showed similar results to those found in previous analyses, as outlined in Table 4.

Table 1 – Correlation analysis between expectation of support for care and other variables, 2008-2009, Campinas, São Paulo, Brazil

Variable	Anticipated support for care		*P* value
	Yes	No	
Gender			
Female	402 (87.20)	59 (12.80)	0.018
Male	196 (93.33)	14 (6.67)	
Age (years)			
65–74	415 (89.44)	49 (10.56)	0.691
≥ 75	183 (88.41)	24 (11.59)	
Living arrangements			
Alone	83 (77.58)	24 (22.42)	**< 0.001**
Accompanied	510 (91.39)	48 (8.60)	
Number of diseases			
0–2	345 (90.32)	37 (9.68)	0.300
≥ 3	252 (87.81)	35 (12.19)	
Frailty			
Non-frail	271 (90.03)	30 (9.96)	0.494
Pre-frail and frail	327 (88.37)	43 (11.62)	
Functional incapacity			
AADLs			
none	50 (98.03)	1 (1.96)	0.034
≥ 1	535 (98.84)	70 (1.15)	
IADLs			
none	441 (89.45)	52 (10.54)	0.548
≥ 1	151 (70.83)	21 (29.16)	
BADLs			
none	532 (89.41)	63 (10.58)	0.830
≥ 1	62 (88.57)	8 (11.42)	
General incapacity			
none	38 (97.44)	1 (2.56)	0.085
≥ 1	551 (88.58)	71 (11.41)	
Self-rated health			
Poor or very poor	29 (74.36)	10 (25.64)	
Regular	212 (89.83)	24 (10.17)	**0.009**
Very good or good	354 (90.31)	38 (9.69)	

Table 2 – Univariate logistic regression for lack of anticipated support for care, 2008-2009, Campinas, São Paulo, Brazil

Variables	Categories	*P* value	O.R.*	CI 95% O.R.
Gender	Male (ref.)	-	1.00	-
	Female	**0.020**	2.06	1.12–3.77
Age (years)	60–74 (ref.)	-	1.00	-
	≥ 75	0.691	1.11	0.66–1.87
Living arrangements	Accompanied (ref.)	-	1.00	-
	Alone	**< 0.001**	3.07	1.79–5.28
Number of diseases	0 a 2 (ref.)	-	1.00	-
	≥ 3	0.301	1.30	0.79–2.11
Frailty	Non-frail (ref.)	-	1.00	-
	Pre-frail or frail	0.494	1.19	0.73–1.95
Incapacity in IADLs	0 (ref.)	-	1.00	-
	≥ 1	0.549	1.18	0.69–2.02
Incapacity in AADLs	0 (ref.)	-	1.00	-
	≥ 1	0.065	6.54	0.89–48.05
Incapacity in BADLs	0 (ref.)	-	1.00	-
	≥ 1	0.830	1.09	0.50–2.38
General incapacity	0 (ref.)	-	1.00	-
	≥ 1	0.120	4.90	0.66–36.21
Self-rated health	Good or very good (ref.)	-	1.00	-
	Regular	0.847	1.06	0.62–1.81
	Poor or very poor	**0.004**	3.21	1.45–7.10

*Notes: *OR = Odd ratio for lack of anticipated support for care; (n = 598 with positive answer and n = 73 with negative answer); CI 95% OR = Confidence interval of 95% for the odds ratio; Ref.: reference.*

Table 3 – Multivariate logistic regression for lack of anticipated support for care, 2008-2009, Campinas, São Paulo, Brazil

Variables	Categories	*P* value	O.R.*	CI 95% O.R.
Living arrangements	Accompanied (ref.)	-	1.00	-
	Alone	**< 0.001**	3.36	1.93–5.86
Self-rated health	Good or very good (ref.)	-	1.00	-
	Regular	0.901	0.97	0.55–1.68
	Poor or very poor	0.002	3.74	1.65–8.48

*Notes: *OR = Odds ratio for lack of anticipated support for care; (n = 572 with positive answer and n = 71 with negative answer); CI 95% OR = Confidence Interval of 95% for odds ratio; Stepwise criterion for variable selection.*

Table 4 – Multivariate logistic regression for lack of anticipated support for care, controlled by gender and age, 2008-2009, Campinas, São Paulo, Brazil

Variables	Categories	*P* value	O.R.*	CI 95% O.R.
Living arrangements	Accompanied (ref.)	-	1.00	-
	Alone	**< 0.001**	3.10	1.75–5.49
Self-rated health	Good or very good (ref.)	-	1.00	-
	Regular	0.940	0.98	0.56–1.71
	Poor or very poor	0.003	3.45	1.51–7.88

*Notes: *OR = Odd ratio for lack of anticipated support for care; (n = 572 with positive answer and n = 71 with negative answer); CI 95% OR = Confidence Interval of 95% for odds ratio; Stepwise criterion for variable selection.*

DISCUSSION

This study included community-dwelling older adults with preserved cognition and functional capacity. Therefore, older individuals who were restricted to their homes, with physical limitations and major cognitive impairments, did not have their anticipated support for care investigated. This is certainly one of the main limitations of the current study. In addition, considering the transversal design of this epidemiological study, it is not possible to draw cause and effect inferences between dependent and independent variables; it was only possible to identify some associations with the anticipated support for care of these individuals.

Although the great majority of participants referred positive anticipated support for care, a large parcel of these individuals reported having only one person at their disposition in case they needed help. Considering that participants often consider their spouses as their source of support and that these people are often older people themselves, it is possible to affirm that both would be in risk for lack of support[17]. Results also demonstrated that those individuals who lived alone or rated their current state of health as being poor or very poor were in higher risk for lack of anticipated support for care. Another investigation carried out in Sao Paulo, Brazil, showed that a similar profile of community-dwelling older individuals had low levels of received social support[18]. Considering that, it is possible to affirm that these individuals not only had lack of anticipated support, but in fact, they did not have any source of support available for them in case they needed help.

The literature points out that the larger the number of people living with the older person, the better will be his or her financial situation and affection received[19]. When living with their children, older adults often collaborate financially with the family and in turn they receive the care they need, in a two-way direction of intergenerational support[20]. Accordingly, even though living alone may mean better health conditions and functional capacity, older individuals living alone may have the risk of being in care need and have no one to help them, which put them in a vulnerable economic and social situation.

This is a concerning, considering that the number of older adults living alone in Brazil is increasing. Indeed, recent national statistics[21] showed that there has been an increase of 215% in the number of older people living alone from 1992 to 2012, and the great majority of these people are women. Despite this alarming news, current public policies consider the community as being the best place for the older person to live and to be cared for, in order to allow his or her autonomy, identity and dignity[22].

Even though these policies aim to broaden the access of older individuals to health care and to reconsider individuals' homes as ideal therapeutic environments, these policies automatically exclude those people who do not have a strong informal network of support available. These people will not receive the adequate support they need, as no other alternative is in place to support them. In other words, since the current national care policies are dependent upon the care provided by families and friends to older individuals, the great parcel of the older people living alone and with lack of anticipated support for care showed in the present study will often do not receive the support that they need.

Another concerning aspect raised in this study is the fact that participants who rated their current state of health as being poor or very poor often were in higher risk for lack of anticipated support for care when compared with those participants who rated their health as being regular, good or very good. Even though other studies correlating the same variables were not identified in the literature, recent investigations demonstrate that perceived state of health in directly associated with the quality of received support in older adults[23-24]. Moreover, the lifestyle and the objective measures of health state are often associated with positive experiences of social support within this population[25]. Among some of the consequences of a poor self-rated health, older people may be present poorer functional capacity[26] and higher mortality risks[27] when compared with those with better perceived health.

Similar to other research[28], the current study demonstrates that the perceived state of health of older individuals was relatively consistent with objective measures of their general state of health. Despite their relative state of independence, the majority of participants reported having three or more diseases and were classified as being frail or pre-frail, which put them in risk for dependence for the performance of their ADLs in the near future[29]. Finally, even though other studies have identified that better functional capacity is often associated with the presence of anticipated support for care[30], this association was not found in the current study.

Considering these findings and the increasing older population living alone in Brazil, associated with increasing prevalence of chronic and disabling diseases and the increasing need for care within this population, it is necessary to reflect upon the current formal and informal support networks available to these people. Policies should be reviewed and strategies should be in place to support these people, aiming to improve their subjective and objective psychological and physical health outcomes, helping them to maintain their autonomy and well-being. Health professionals must be aware of these care demands and should seek to identify risk factors for lack of anticipated support for care when planning and delivering care.

CONCLUSION

This investigation showed that community-dwelling older adults who live alone and those with poor or very poor self-rated health are in higher risk for lack of anticipated support for care. These results shall be used to guide public social and health policies focused on the care for older adults, since the profile of older adults in risk is increasing in Brazil. It is necessary to reflect upon the current formal network of support available for these individuals in order to understand how the anticipated support for care is longitudinally associated with other variables, as well as with other measures of social support, such as perceived and received support.

With regards to the impact of this research to health practice, the authors highlight the importance of including subjective measures of evaluation of care, such as anticipated support for care, as this showed to be a practical and sensitive measure, useful for clinical practice. This variable should be included as part of the care plan of nurses in order to provide the necessary care to older individuals living in the community, according to their specific needs.

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