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Disability and Care Dependency of Older Adults

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Content

Foreword

Each chapter corresponds to a scientific article published, submitted or in preparation for submission to a peer-reviewed journal. I am the only author or lead author in all papers.

The first article, “Transitions across states with and without difficulties in performing activities of daily living and death: a longitudinal comparison of ten European countries” is of my authorship and is under review in the *European Journal of Ageing* (submitted in November 2022).

In the second article, “Dependency change with aging and associated factors in Uruguay: a cohort study," I am the first and corresponding author and the coauthors are Maximiliano Machado and Graciela Muniz Terrera. This paper was published in *Journal of Aging and Health* (see https://doi.org/10.1177/08982643211017726).

The third article, “Operationalization of care dependence in community-dwelling older adults: a systematic review”, is in preparation for submission to *Journal of Epidemiology & Community Health*. I am the first and corresponding author and the coauthors are Maira Colacce, Julia Córdoba and Graciela Muniz Terrera. This work is part of the project *“Programa de Inclusión Social 2019, ID 28, Caracterización y proyección de la población en situación de dependencia en Uruguay”* funded by *Comisión Sectorial de Investigación Científica*, *Universidad de la República*, Uruguay.

Introduction

In this dissertation I focus on the analysis of trajectories of disability and care dependence of older adults with aging, taking a global perspective of the problem and analyzing conceptual and measurements differences.

Population aging is global and concerns policy makers in high, middle and low-income countries, as older people are affected by disability and care dependence issues that may hamper their well-being and that of their families (Barnay and Juin, 2016; Bloom et al., 2010; Navarro Espigares et al., 2008; Van Houtven and Norton, 2004). There is a need to better understand the disability and dependency trajectories of older adults and their relationship with socio-demographic characteristics and institutional or cultural context. In recent decades, low- and middle-income countries have experienced an increase in life expectancy which resulted in a higher proportion of older adults in their age structures (Bloom et al., 2010; Colombo et al., 2011; Madero-Cabib et al., 2021; Matus-López, 2015; Prina et al., 2020; Sousa et al., 2010; Villalobos Dintrans and González Bautista, 2020). Although, demographic transition is perceived as a good symptom for pursuing development, it can also be challenging as it transforms the age structure of the population which stretches health and social care systems (Galiani et al., 2017; United Nations, 2020).

Previous analyses reported that with increasing age, disability, and care dependency also increase, and this poses the question: for how long will older adults have daily difficulties and hence will need care? (Abdi et al., 2019; Barnay and Juin, 2016).

In order to contextualize the analyzes, it is important to state three interrelated concepts that will be present over this work: disability, care dependency and long-term care. Disability has been defined as an umbrella term for impairments, activity limitations, and participation restrictions,

and has a dynamic interaction between health conditions and contextual factors (personal and environmental) (WHO, 2001; WHO & WB, 2011).

Care dependency is a multidimensional construct, but here I refer to the need for support to perform Activities of Daily Living due to lack or loss of physical or mental health, and arises when a person is no able to perform the tasks of daily living without the help of others and cannot be compensated by the environment or use of assistive devices (Harwood et al., 2004, WHO, 2015).

Finally, Long-Term Care is the range of services needed by care dependents (Colombo et al., 2011; Kraus et al., 2011) and may be divided in *informal care*, provided by informal caregivers, such as spouses/partners, friends, neighbors, etc., and *formal care*, supplied on the basis of a contractual relationship with the public or private sector (paid service with own funds or transfers).

The effort to define and operationalize disability, facilitates international comparison, harmonization of data, etc., but no consensus has been done for care dependence. The patterns of aging are most likely heterogeneous and previous studies have adopted latent approaches to assess heterogeneity of health, disability, and care dependence, or applied different measures of outcomes related to aging process to assess this heterogeneity (Amengual et al., 2021; Marroig et al., 2022; Millán-Calenti et al., 2010; Montanari et al., 2011). However, different ways of assessing disability and care dependency for older adults may hamper comparability of the results.

The contribution of this thesis is to improve knowledge of aging trajectories to inform long-term care policies, applying a longitudinal and global perspective. It contributes to the international comparison of the results in order to assess external validity and robustness of the

results, using a harmonized methodology for European countries. It contributes to the knowledge of change in disability and care dependency using longitudinal studies in Uruguay, the most aged Latin American country with a national care system initiated in 2015. Finally, the review of the literature in the last two decades contributes to future research aimed at dependent older population, and may be useful for future research that analyzes: how to target long-term care policies, how to ensure an adequate quality of life for community-dwelling older adults and their families, how to achieve sustainability of these policies, and how to perform international comparison and harmonization.

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Chapter 1: Transitions across states with and without difficulties in performing activities of daily living and death: a longitudinal comparison of ten European countries

Abstract

Aging has been related to the onset of disability and dependency in older adults. There is a need to better understand the disability and dependency trajectories of older people and their relationship with socio-demographic characteristics and institutional or cultural context.

This study analyses the role of age, sex, education, and self-perceived health on transitions across states of disability, dependency, and death. Additionally, it addresses heterogeneity across European countries and inconsistencies of different measures of disability.

Multi-state models were adjusted to analyze the role of risk factors on transitions to disability, dependency, and death. Disability and dependency were measured by difficulties in performing Activities of Daily Living (ADLs). Data comes from the Survey of Health, Ageing and Retirement in Europe in 2004-2013, considering individuals aged 65 and older at baseline from Austria, Belgium, Denmark, France, Germany, Italy, the Netherlands, Spain, Sweden, and Switzerland.

The results showed that transitions to disability and dependency varied with age, sex, education and self-perceived health considering death. The probability of transition to disability or dependency increases until 70 years old for all countries. However, there was heterogeneity regarding sex differences in the transitions to disability and dependency with aging. Women live with difficulties and may need help for longer than men in most countries.

Care policies should take into account sex differences in order to decrease the burden of care on informal caregivers, particularly in countries where care systems are absent or partially developed and with high level of family obligations to care needs.

Keywords: Aging; Care Dependency; Activities of Daily Living; Multi-State Models; Longitudinal analysis; SHARE

JEL code: C33, J14, I10

Background

Aging has been related to the onset of disability and care dependence in older adults, and help from others may be needed daily (Barnay and Juin, 2016; Navarro Espigares et al., 2008; Van Houtven and Norton, 2004). Some individuals start having difficulties and may require help earlier in life while others may preserve independence for longer. The different trajectories of the individuals towards disability and dependency with aging could vary according to socio-demographic characteristics and may be related to the institutional or cultural context, the type of help needed, the met or unmet care needs, and their quality of life (Abdi et al., 2019; Geerts and Van den Bosch, 2012).

The health of the older people is characterized by the interaction among comorbidity, disability and frailty, which are also associated with the use of health care services and the need for help for daily activities (Fried et al., 2004). With increasing age, the risk of disability and care dependence tends to increase, as functional or mental impairments result from declines in health (Arrighi et al., 2017; Barnay and Juin, 2016; Carmona-Torres et al., 2019).

Disability and care dependence are complex and multidimensional constructs related to health conditions and contextual factors. Disability is defined as an umbrella term for impairments, activity limitations and participation restrictions, and represents the negative aspects of the interaction between the individual's health condition and personal and environmental factors (WHO, 2001). Meanwhile, care dependence is defined as the need for human help or care beyond that habitually required (Harwood et al., 2004). Much of the literature on functional capacity, disability, and care dependency of older adults have used the Activities of Daily Living (ADLs) to operationalize these constructs (Amengual et al., 2021; Carmona-Torres et al., 2019; Edjolo et al., 2016; Jerez-Roig et al., 2018; Lima et al., 2018; Millán-Calenti et al., 2010;

Rodríguez-Sampayo et al., 2011; WHO, 2015). Typically, ADLs are classified into Basic Activities of Daily Living (BADLs) and Instrumental Activities of Daily Living (IADLs), thus representing the diversity and multidimensionality of the constructs (Katz et al., 1963; Lawton and Brody, 1969). The ability to perform BADLs is intended to assess functional capacity related to the individual's physical condition, whereas the assessment of IADLs skills is assessing activities that are more cognitively demanding and often approximate the potential of older adults to live independently in the community (Millán-Calenti et al., 2010). Recently, Advanced Activities of Daily Living (AADLs), that includes social and community participation, communicating and making decisions, are also considered (WHO, 2001).

This study aims to deepen the understanding of aging trajectories towards states with and without difficulties in performing ADLs, while simultaneously considering the transition to death. Furthermore, it aims to contribute to a better understanding of the risk factors that shape these trajectories. In particular, it addresses the sex differences in these trajectories across European countries and contextualizes the results in the cultural and institutional contexts of these countries.

Previous literature on disability and care dependency of older people in Europe

There is wide literature that focuses on disability of older adults in Europe. For instance, a previous cross-sectional study estimated the prevalence of disability, defined by the difficulties in performing BADLs, using data from the Survey of Health, Ageing and Retirement in Europe (SHARE) in 2015 (Jerez-Roig et al., 2018). The authors reported regional differences across European regions (Northern, Central, Eastern and Southern), particularly they found that older adults with disabilities from East Europe presented the most disadvantaged health profile, followed by the Southern region, and older adults living in the Northern region showed the most

advantaged characteristics. Another study reported a considerable prevalence of disability that has been slowly decreasing in the period 2009 to 2017 (Carmona-Torres et al., 2019). Using cross-sectional data from Spain in different years they also reported that disability was associated with female sex, advanced age, and lower educational attainment, among others risk factors. Likewise, other studies found that other health conditions such as dementia, stroke, limb impairment, and depression were identified to be key contributors to disability and care dependence (Prina et al., 2020). Further, it was argued that self-perceived health is the most informative measure of health status predicting mortality in population studies (Jylhä, 2009).

The 'male-female health-survival paradox' postulates that women have longer Life Expectancy (LE) but live in poorer health, has been well-documented (Austad, 2006; Bora and Saikia, 2015; Cameron et al., 2010; Crimmins et al., 2011; Lima et al., 2018; Thorslund et al., 2013). In a cross-sectional study from 2004, it was reported that older women have worse functioning and higher levels of disability in performing IADLs than men, but disability in performing BADLs was not found to be different between men and women in the United States and in European countries (Crimmins et al., 2011). Moreover, using cross-sectional data from India in 2007, sex differences were shown in self-reported disability (Bora and Saikia, 2015). Besides, women in older ages presented greater activity limitations and there was evidence of heterogeneity across European countries in 2011/12 (Lima et al., 2018).

Sex patterns of difficulties in performing BADLs and/or IADLs may also be affected by the different roles of men and women in household activities, and a comparison across different cultures and institutional contexts could provide new insights into this heterogeneity (Millán-Calenti et al., 2010). Hence, differences between men and women may be relevant to inform actions that ensure the quality of life of older adults despite their difficulties and care needs

(Beach et al., 2018). Thorslund and co-authors (2013) reported that the female advantage in LE, found worldwide has been narrowing. However, the differences in disability-free life expectancies, could still be relevant to understand for how long older adults live with difficulties in BADLs and/or IADLs that may require help (Moreno et al., 2020; Solé-Auró et al., 2015).

While many previous studies addressed differences in disability between older women and men using cross-sectional data, there is relatively less literature that uses a longitudinal perspective and considers death attrition simultaneously. However, some studies have implemented longitudinal perspective to analyze health trajectories of older adults. For instance, Amengual and co-authors (2021) developed a methodology to classify individuals into groups, exploiting health information from panel data, and they estimate transitions across latent categories (health groups) and death, conditioning on socio-demographic characteristics and current health status. In turn, Arrighi and co-authors (2017) analysed the socioeconomic determinants of transitions across disability and frailty states in European countries from 2004 to 2011, and reported an overrepresentation of socioeconomically disadvantaged groups in the current cohorts of dependent older adults.

On the other hand, some studies aimed to understand the mix of care used by dependent older people in terms of formal or informal care. For instance, Geerts and Van den Bosch (2012) analyzed the transitions between formal and informal care utilization across nine European countries between the wave 1 (2004/2005) and wave 2 (2006/2007) of SHARE. Their results suggested that, whilst rates of formal care utilization continue to differ considerably across European countries, formal care allocation practices are not very different across Northern and Continental European welfare states. In addition, they explored how macro-contextual factors affect transitions in formal and informal care utilization by older Europeans considering two

dimensions in which Long-Term Care (LTC) systems could vary: the degree of familial obligations (cultural dimension), and the existence of universal entitlements to public support, in-kind and/or by means of cash benefits (institutional dimension). Briefly the authors state that, in Spain and Italy there is a high degree of family obligations in the cultural dimension and in the institutional dimension a universal needs-based system is absent or partial. In contrast, in the Netherlands, Sweden and Denmark, widely accessible public services coexist with a cultural dimension characterized by limited family obligations. In Austria and Germany, the needs-based entitlement system coexists with a culture of high levels of family obligations. Finally, the authors identify a medium level of family dependency obligations in France and Belgium, coexisting with a universal needs-based entitlement system in France, while in Belgium this system is either non-existent or partial (Geerts and Van den Bosch, 2012). Additionally, Geerts and Van den Bosch (2012) analyzed the individual determinants of care utilization based on the behavioral model for the determinants of healthcare utilization proposed by Andersen and colleagues (Andersen, 2008). Within the individual determinants proposed in that model there are the need factors, which represent the most immediate cause of health service use. These factors include measures of perceived and evaluated illness, particularly, age and limitations in ADLs have consistently been found to be strongly associated with utilization of home care services (Geerts and Van den Bosch, 2012).

Aim and contributions

Although the literature on disability in older adults is extensive, there is scarce research examining the transitions to disability considering simultaneously the transition to death, with a longitudinal perspective during a long period of time. A better understanding of disability, dependence and how sex differences model trajectories towards disability and death, is critical

to inform care policies designed to improve quality of life of older people living in the community and their families. Consideration of the competing risks between transitions to disability and death is a key issue in order to draw unbiased inferences in longitudinal studies on aging. Moreover, assessing disability of older adults is particularly relevant in the European countries were persistent aging of the population is putting pressure to the sustainability of social and health care systems. Also it is important to ensure comparability of results across countries, as this can provide new insights about trajectories to disability in different institutional and cultural contexts (Geerts and Van den Bosch, 2012). As a result, this study aims to analyze the role of socio-demographic characteristics (age, sex, and education) and health condition (assessed by the self-perceived health) on transitions towards states with and without difficulties in ADLs considering simultaneously the transition to death. This analysis considers ten European countries that participated in the SHARE study during the period 2004-2013. Additionally, it aims to address the heterogeneity across these European countries, particularly regarding sex differences in the patterns of transition towards disability and death, relating these results to the institutional and cultural contexts. Furthermore, to assess the multidimensionality of disability, the construct is approached by considering difficulties in different types of ADLs, namely BADLs and IADLs.

This analysis seeks to improve knowledge of aging trajectories to inform long-term care policies, applying a longitudinal perspective that takes into account death, sex differences, the multidimensionality of disability, and contextualizing the results regarding differences in cultural and institutional dimensions of the European countries analyzed. Thus, the contribution is to better understand the shape of aging disability trajectories during the decade 2004-2013 considering death, and focusing on sex and cross-country differences. The analytical approach

ensures comparability across European countries in order to contextualize the results into the different cultural and institutional contexts. Finally, this work contributes to analyze the heterogeneity in the role of the associated factors on the difficulties to perform different types of ADLs.

Methods

Data

The data comes from the SHARE study, a multidisciplinary and cross-national panel database where information on health, socio-economic status and social and family networks of individuals aged 50 or older in Europe has been collected since 2004 across European countries (Börsch-Supan et al., 2005). For each participating country, a separate ethical approval was obtained by the respective ethics committees whenever it was required (for more details on the ethical approvals see: http://www.share-project.org/fileadmin/pdf_documentation/SHARE_ethics_approvals.pdf).

This current study includes data of people aged 65 or older at baseline, from 10 European countries (Austria, Belgium, Denmark, France, Germany, Italy, Netherlands, Spain, Sweden and Switzerland) where the information was collected over 4 occasions (waves 1, 2, 4 and 5) covering the period from 2004 to 2013. The total analytical sample for the ten countries combined is 19691 individuals. Table 1 presents descriptive characteristics at study entry of the sample in each country. Only respondents with valid data on the difficulty in performing ADLs, education and self-perceived health (SPH), and also with two known states during the period 2004-2013 were included in the analyses. Death status and age at death were retrieved from SHARE data up to wave 7 (2017).

Table 1. Descriptive characteristics at study entry (N = 19691)

Country	N	Age	Female	High education	Better health	ND B&IADLs	D B&IADLs	ND BADLs	D BADLs	Deaths
Austria	2453	73.26 (6.49)	1407 (57.36)	559 (22.79)	664 (27.07)	1861 (75.87)	592 (24.13)	2123 (86.55)	330 (13.45)	245
Belgium	2493	73.45 (6.87)	1374 (55.11)	592 (23.75)	585 (23.47)	1791 (71.84)	702 (28.16)	2021 (81.07)	472 (18.93)	312
Denmark	1345	72.83 (6.84)	734 (54.57)	387 (28.77)	597 (44.39)	1059 (78.74)	286 (21.26)	1181 (87.81)	164 (12.19)	312
France	2647	74.21 (7.04)	1531 (57.84)	365 (13.79)	381 (14.39)	1975 (74.61)	672 (25.39)	2210 (83.49)	437 (16.51)	328
Germany	1282	71.43 (6.00)	643 (50.16)	332 (25.90)	182 (14.20)	1020 (79.56)	262 (20.44)	1113 (86.82)	169 (13.18)	159
Italy	2054	71.77 (6.08)	1051 (51.17)	88 (4.28)	316 (15.38)	1655 (80.57)	399 (19.43)	1763 (85.83)	291 (14.17)	317
The Netherlands	1573	71.94 (6.35)	816 (51.88)	281 (17.86)	407 (25.87)	1320 (83.92)	253 (16.08)	1432 (91.04)	141 (8.96)	214
Spain	2380	74.24 (7.10)	1294 (54.37)	115 (4.83)	288 (12.10)	1709 (71.81)	671 (28.19)	1906 (80.08)	474 (19.92)	552
Sweden	1873	73.04 (7.22)	969 (51.74)	343 (18.31)	678 (36.20)	1481 (79.07)	392 (20.93)	1640 (87.56)	233 (12.44)	455
Switzerland	1591	73.11 (6.63)	826 (51.92)	175 (11.00)	589 (37.02)	1404 (88.25)	187 (11.75)	1474 (92.65)	117 (7.35)	117

Total	19691	73.09 (6.77)	10645 (54.06)	3237 (16.44)	4687 (23.80)	15275 (77.57)	4416 (22.43)	16863 (85.64)	2828 (14.36)	3011

Notes: Values are sample size and %, or mean and standard deviation for Age. 'High education' indicates that the highest educational attainment is first or second stage of tertiary education according to the International Standard Classification of Education 1997, ISCED-97, coding. 'Better health' represents that the person reported an "Excellent" or "Very good" self-perceived health, as opposed to reporting "Good", "Poor" or "Fair" self-perceived health. Abbreviations: ND: No Disability; D: Disability; B&IADLs: Basic and/or Instrumental Activities of Daily Living; BADLs: Basic Activities of Daily Living.

Variables and measures

For the purposes of the analysis, a series of dummy variables were derived to account for differences in education (1= the highest educational attainment is first or second stage of tertiary education according to the International Standard Classification of Education 1997, ISCED-97, coding, 0= otherwise), sex (1= Female, 0= Male) and self-perceived health (1= declared "Excellent" or "Very good" self-perceived health, 0= declared "Good", "Poor" or "Fair" self-perceived health). Age and age at death were measured in years.

Activities of daily living and the disability state. Difficulties in performing BADLs and/or IADLs were considered to determine states. Six BADLs were considered: 1- dressing, including putting on shoes and socks, 2- walking across a room, 3- bathing or showering, 4- eating, such as cutting up your food, 5- getting in or out of bed, and 6- using the toilet, including getting up or down. Whilst six IADLs were: 1- preparing a hot meal, 2- shopping for groceries, 3- making telephone calls, 4- taking medications, 5- doing work around the house or garden, and 6- managing money, such as paying bills and keeping track of expenses.

At study entry, individuals were classified into two possible states. One represents a state without difficulties in performing ADLs (ND) and the other a state with difficulties in performing any ADLs (D). As information about death becomes available, the individuals were classified in the death state (Death).

Two operationalizations of the D state were assessed. First, the D state was determined when the individual had difficulties in performing at least one BADLs and/or IADLs, corresponding to a comprehensive disability state which considers different types of ADLs (Millán-Calenti et al., 2010). I refer to this operationalization of D state as "disability state". Secondly, an individual was classified in the D state when declared to had difficulties in performing at least

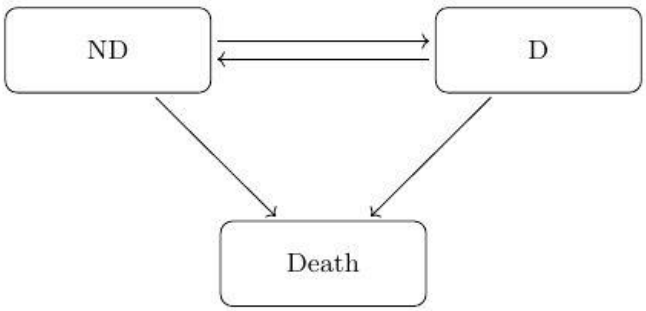
one BADLs, without considering the difficulties in performing IADLs. This second operationalization could be considered a "proxy" of care dependency state. Like in previous studies, having one or more difficulties in BADLs would be probably associated with the need for help to perform daily activities (Rodríguez-Sampayo et al., 2011) and considers also the hierarchy in the loss of functionality with increasing age (Dunlop et al., 1997; Edjolo et al., 2016a). Although it is a "proxy" of care dependence, I refer to this operationalization of D state as "dependency state".

Statistical Approach

Multi-State Models (MSM) were used to analyze the transitions across states with and without difficulties in performing ADLs and death. This approach allows to model transitions between the three states: ND, D and Death, and examine the role of risk factors on all transitions simultaneously. As previously mentioned, the D state corresponds to a disability state, with difficulties in performing BADLs and/or IADLs, or a dependency state, with difficulties in performing BADLs, depending on the operationalization used. See Figure 1 for a pictorial representation of the three state model.

Two empirical strategies were implemented. The first strategy assessed simultaneously the role of age, sex, education and self-perceived health on transitions between the three states, with pooled data of individuals from ten European countries. In this strategy, age was included as a covariate on all transitions modelled. Sex, education, self-perceived health, and country specific fixed-effects were included on all transitions except for the backward transition from D to ND state. These effects were excluded from the backward transition, as the lower number of individuals transitioning from D to ND makes it difficult to model the effects of all covariates in this transition.

Figure 1. Three-state model for states with and without difficulties in performing ADLs and death



Notes: D state was operationalised in two ways: 1- at least one difficulty in performing Basic Activities of Daily Living and/or Instrumental Activities of Daily Living, 2- at least one difficulty in performing Basic Activities of Daily Living. The arrow illustrates transitions modelled over time. Abbreviation ND: No Disability; D: Disability; BADLs.

The second strategy focuses on assessing the heterogeneity among these ten European countries with respect to the role of sex in transitions between disability states. In this case, the MSM were estimated for each country allowing the cross-country comparison of the role of sex on the transitions. Hence, age and sex were included as covariates on all transitions, with the exception of the transition from D to ND, because of the same reason as before.

In both strategies, age at death was used to identify death status. In cases where the individual was still alive at the last wave considered (wave 5 in 2013) but the age at death was known from a later wave (wave 6 in 2015 or wave 7 in 2017) then it was incorporated in the analysis. Interval censoring was used.

The *msm* package for R (Jackson, 2011) was used to estimate the MSM. As a result, we obtain the hazard ratios of the covariates over the transitions and their confidence intervals. The hazard ratios represent the instantaneous transition rate and if they are greater than one indicate a higher

instantaneous transition risk conditional on the covariates. In addition, we calculate the transition probability across states and its evolution with age.

After the MSM were estimated, the *elect* package for R was used to estimate LE (van den Hout, 2016). This package fits a multinomial regression model for state prevalence to estimate total and marginal LEs. Total and disability-free life expectancies were estimated to examine the role of covariates on LE and time remaining disability-free. The analysis was performed for the two MSM resulting from both operationalizations of D state. LE was estimated for individuals aged 65 years according to sex.

Results

Role of age, sex, education and self-perceived health on disability transitions

Effects of covariates on transitions between disability or dependency states and death with pooled data from ten European countries are presented in Table 2. A visual depiction of the results illustrating the hazard ratios for the effect of age and sex (1= Female vs. 0= Male) on transitions are presented in Figure 2 and Figure 3, respectively.

Table 2. Hazard ratio and 95% confidence intervals for the effect of covariates on transitions

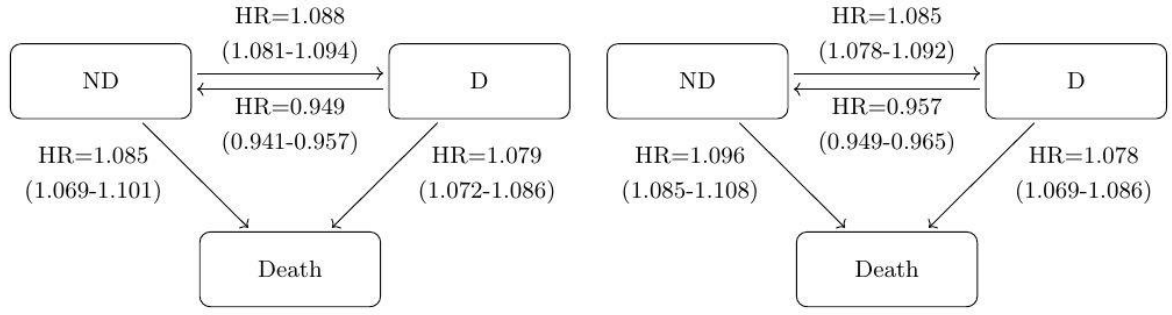
	Difficulties in BADLs and/or IADLs				Difficulties in BADLs			
	Age	Female	High education	Better health	Age	Female	High education	Better health
ND-D	1.088* (1.081-1.094)	1.248* (1.168-1.333)	0.791* (0.715-0.875)	0.434* (0.395-0.478)	1.085* (1.078-1.092)	1.185* (1.098-1.280)	0.784* (0.695-0.885)	0.436* (0.387-0.492)*
ND-Death	1.085* (1.069-1.101)	0.429* (0.350-0.525)	0.843 (0.652-1.090)	0.530* (0.416-0.677)	1.096* (1.085-1.108)	0.511* (0.441-0.592)	0.947 (0.781-1.148)	0.476* (0.388-0.583)
D-ND	0.949* (0.941-0.957)	---	---	---	0.957* (0.949-0.965)	---	---	---
D-Death	1.079* (1.072-1.086)	0.644* (0.584-0.710)	0.996 (0.838-1.183)	0.629* (0.491-0.804)	1.078* (1.069-1.086)	0.665* (0.592-0.748)	0.874 (0.702-1.090)	0.626* (0.448-0.876)

Notes: The table shows the effects of covariates on the risk of transitioning with pooled data from ten European countries. 'High education' indicates that the highest educational attainment is first or second stage of tertiary education according to the International Standard Classification of Education 1997, ISCED-97, coding. 'Better health' represents that the person reported an "Excellent" or "Very good" self-perceived health, as opposed to reporting "Good", "Poor" or "Fair" self-perceived health. Abbreviations: ND: No Disability; D: Disability; BADLs: Basic Activities of Daily Living; IADLs: Instrumental Activities of Daily Living. * 5% significant ratio.

Age

Increasing age was associated with higher risk of transition to death, either from ND or D states. This result holds for both operationalizations of D states, specifically when considering difficulties in performing BADLs and/or IADLs (HR = 1.088 CI = [1.081, 1.094]) as well as when considering only difficulties in BADLs (HR = 1.085 CI = [1.078, 1.092]). With regards to the reverse transition, the results suggested that increasing age was associated with a decreasing risk of transitioning from D to ND, also in both operationalizations of D state (see Figure 2).

Figure 2. Three-state model with the effect of age on transitions with pooled data



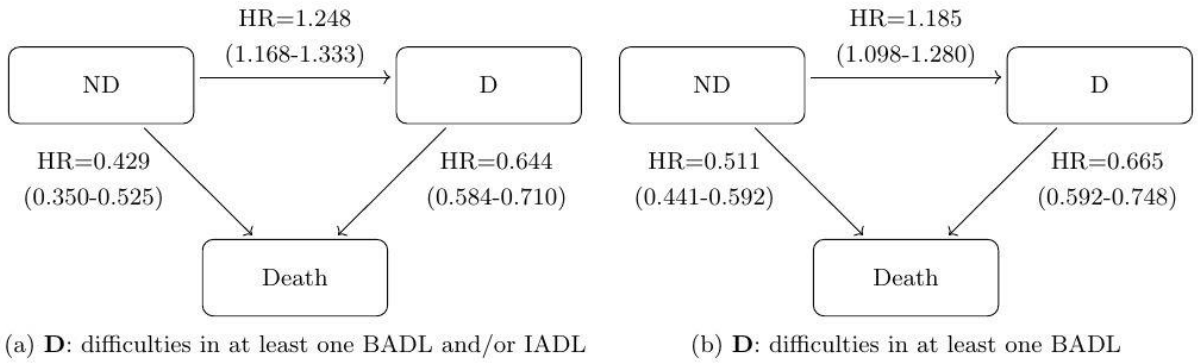
(a) **D**: difficulties in at least one BADL and/or IADL (b) **D**: difficulties in at least one BADL

Notes: The figures include the HRs (95% confidence intervals) with pooled data from ten European countries for both operationalizations of D. Abbreviations: ND: No Disability; D: Disability. HR, hazard ratio; BADLs: Basic Activities of Daily Living; IADLs: Instrumental Activities of Daily Living.

Sex

Being female was associated with lower risk of transitioning from ND or from D to death and higher risk of transitioning from ND to D for both operationalizations: considering BADLs and/or IADLs (HR = 1.248 CI = [1.168, 1.333]) or only BADLs (HR = 1.185 CI = [1.098, 1.280]) (see Figure 3).

Figure 3. Three-state model with the effect of sex on transitions with pooled data



(a) **D**: difficulties in at least one BADL and/or IADL (b) **D**: difficulties in at least one BADL

Notes: The figures include the HRs (95% confidence intervals) with pooled data from ten European countries for both operationalizations of D. Abbreviations: ND: No Disability; D: Disability. HR, hazard ratio; BADLs: Basic Activities of Daily Living; IADLs: Instrumental Activities of Daily Living.

Education

Having a high educational attainment was associated with lower risk of transitioning from ND to D, when D is a disability or a dependency state. However, high level of education was not significant associated with the risk of transitioning to death (see Table 2).

Self-perceived health

Having reported a better self-perceived health was associated with a lower risk of transitioning from ND to D for both operationalizations, and transitioning to death irrespective of the initial state (see Table 2).

Cross-country comparison of sex differences

Sex differences on disability transitions considering death

The results showed great heterogeneity among the European countries regarding the effect of sex on transitions to disability or dependency and death (see Table 3). Also, there were inconsistencies within countries when different operationalizations of the D state were used.

When difficulties in performing BADLs and/or IADLs are considered, and D represents a disability state, Spain, Italy, The Netherlands, Austria and Belgium showed a higher risk of transition from ND to D for women than men. However, when considering only difficulties in performing BADLs and the D state represents a dependency state, sex differences are statistically significant only in Spain, Italy and Belgium.

Regarding the transitions to death, most of the countries showed a lower risk of transition for women than men, for both operationalizations and irrespective of the initial state. However, there were some hazard ratios not statistically significant (i.e., for Belgium, Germany and Austria when the initial state is ND and D is a disability state).

Fitting multi-state models also gives the probability of transition between states and how this varies with increasing age (see Figure S1 and Figure S2 in Supplementary material). The results showed that the probability of transitioning to disability and dependency increases until 70 years, consistently across countries. This result suggests that after 70 years old, when this probability is stable, the transition to death is more likely. Also, the probability of transition to disability is higher over time than the probability of transition to dependency and in some countries statistically significant differences between women and men appear (i.e. Spain and Italy), consistent with the result of the hazard ratios (see Figure S1 and Figure S2 in Supplementary material).

Table 3. Hazard ratio and 95% confidence intervals for the effect of sex on transitions by country

	Transition ND - D		Transition ND - Death		Transition D - Death	
Country	Diff. B&IADL	Diff. BADL	Diff. B&IADL	Diff. BADL	Diff. B&IADL	Diff. BADL
Austria	1.365*	1.190	0.477*	0.609*	0.729	0.771
	(1.096-1.700)	(0.926-1.530)	(0.258-0.880)	(0.384-0.968)	(0.503-1.056)	(0.496-1.198)
Germany	1.204	1.057	0.616	0.619	0.692	0.818
	(0.936-1.549)	(0.795-1.405)	(0.301-1.260)	(0.340,1.128)	(0.430-1.114)	(0.474-1.411)
Sweden	1.086*	0.970	0.463*	0.565*	0.842	0.903
	(0.887-1.331)	(0.760-1.238)	(0.271-0.793)	(0.382-0.834)	(0.653-1.086)	(0.660-1.234)
The Netherlands	1.469*	1.201	0.190*	0.348*	0.637*	0.697
	(1.155-1.869)	(0.875-1.648)	(0.069-0.527)	(0.205-0.592)	(0.437-0.929)	(0.430-1.132)
Spain	1.646*	1.609*	0.362*	0.494*	0.627*	0.592*
	(1.388-1.952)	(1.323-1.957)	(0.211-0.620)	(0.332-0.735)	(0.503-0.782)	(0.464-0.755)
Italy	1.562*	1.490*	0.258*	0.364*	0.631*	0.684*
	(1.284-1.901)	(1.198-1.852)	(0.114-0.586)	(0.210-0.630)	(0.476-0.836)	(0.494-0.948)
France	1.172	1.135	0.292*	0.522*	0.702*	0.720*
	(0.988-1.391)	(0.932-1.382)	(0.106-0.801)	(0.297-0.917)	(0.537-0.916)	(0.522-0.994)
Denmark	1.077	1.045	0.725	0.724	0.653*	0.710
	(0.839-1.382)	(0.772-1.415)	(0.435-1.210)	(0.500-1.047)	(0.480-0.889)	(0.470-1.071)
Switzerland	0.968	1.101	0.376*	0.338*	0.482*	0.688
	(0.730-1.282)	(0.777-1.560)	(0.175-0.811)	(0.193-0.590)	(0.266-0.874)	(0.308-1.535)
Belgium	1.242*	1.225*	0.613	0.590*	0.472*	0.461*
	(1.052-1.466)	(1.013-1.482)	(0.315-1.194)	(0.358-0.974)	(0.358-0.623)	(0.331-0.642)

Notes: The table shows the effect of being female on the risk of transitioning. Disability state was determined when the individual had difficulties in at least one BADLs and/or IADLs. Dependency state was determined as a proxy, when the individual had difficulties in at least one BADL. Abbreviations: ND: No Disability; D: Disability; Diff. B&IADL: Difficulties in BADLs and/or IADLs; Diff. BADL: Difficulties in BADLs; HR, hazard ratio; BADL: Basic Activities of Daily Living; IADL: Instrumental Activities of Daily Living. * 5% significant ratio.

Table 4. Life expectancies for male and female participants at 65 years old

	Life expectancies in years (95% CI)[1]		Disability-free life expectancy in years (95% CI)[2]	
Country	Female	Male	Female	Male
Austria	20.87 (20.03,21.72)	18.01 (17.05,18.98)	12.70 (11.86,13.55)	12.74 (11.77,13.70)
Germany	20.98 (19.83,22.13)	18.67 (17.56,19.78)	13.18 (12.04,14.33)	13.13 (12.03,14.24)
Sweden	19.43 (18.61,20.24)	17.19 (16.45,17.93)	14.14 (13.33,14.95)	13.16 (12.42,13.89)
The Netherlands	22.66 (21.51,23.81)	18.11 (17.07,19.15)	14.81 (13.66,15.96)	14.16 (13.12,15.20)
Spain	19.11 (18.48,19.73)	15.97 (15.27,16.66)	11.23 (10.60,11.86)	11.76 (11.07,12.46)
Italy	20.64 (19.87,21.41)	17.69 (16.88,18.50)	12.36 (11.59,13.13)	13.07 (12.26,13.88)
France	22.35 (21.66,23.04)	19.42 (18.65,20.19)	13.05 (12.36,13.74)	12.83 (12.06,13.60)
Denmark	18.80 (17.77,19.83)	16.49 (15.45,17.53)	13.01 (11.99,14.04)	12.42 (11.39,13.46)
Switzerland	24.71 (23.45,25.96)	19.77 (18.67,20.87)	18.16 (16.91,19.42)	15.72 (14.62,16.82)
Belgium	22.94 (22.21,23.66)	18.86 (18.11,19.61)	12.55 (11.82,13.27)	12.54 (11.79,13.29)

Notes: D state is a disability state, and was determined when the individual had difficulties in at least one BADLs and/or IADLs.

[1] Total LE in years. [2] LE in state No Disability irrespective of where you are at a given age.

Total and disability-free life expectancies

Table 4 shows the total and disability-free life expectancies for male and female in each country at 65 years old. Across all countries total LE at 65 years old is higher for women than men. However, the disability-free LE is very similar for women and men in most countries (except Switzerland or Sweden).

Sensitivity analysis

Sensitivity analyses were conducted to assess the robustness of the results regarding the role of sex on the transitions across states in the cross-country analysis. First, we added the covariate indicating high educational attainment to all transitions, with the exception of the transition from D to ND. The results regarding the role of sex on the transitions to disability and dependency were essentially the same as the model that does not include the educational attainment (see Table S1). Secondly, the models were adjusted by self-perceived health, and some differences emerged in Belgium. In the case of dependency, when only BADLs were considered to determine D state, sex differences were statistically significant in Spain and Italy but not in Belgium. However, for disability state (BADLs and/or IADLs) the results were consistent across the different model specifications (see Table S2).

Discussion

This study analysed the role of socio-demographic characteristics and health condition on transitions to states with and without difficulties in performing ADLs in ten European countries, using a longitudinal perspective during the decade 2004-2013. The analytical approach allowed to consider the transition to disability and dependency states and death, and how different factors affect them simultaneously.

In pooled country analyses, the results showed that transitions towards states with and without difficulties in performing ADLs, varied with age, sex, education and self-perceived health. Increasing age was associated with a higher risk of transitioning to disability states and death, and in this latter case irrespective of the initial state. This result was consistent between both measures of disability state: when considering difficulties in performing BADLs and/or IADLs or only difficulties in BADLs. Moreover, in cross-country analyses the effect of age on all transitions is consistence across European countries and both measures of disability state.

Furthermore, in the pooled country analysis, female sex emerged as a risk factor for disability and protective factor for mortality. Regarding education, current results suggested that a higher educational attainment reduces the risk of transition to disability. However, a higher education degree does not affect transition to death. Finally, a good self-perceived health resulted a protective risk factor against disability and mortality in both operationalizations. These results are in keeping with previous studies that have been concerned about the risk and protective factors of disability in older adults (Carmona-Torres et al., 2019; Jylhä, 2009; Prina et al., 2020). In the cross-country analysis, it was possible to compare the differences in trajectories towards disability and dependency considering death, in the different cultural and institutional contexts of the ten European countries. Particularly concerning sex differences, the results are inconsistent across countries and also between both operationalizations of D state, as previous cross-sectional analysis suggested (Jerez-Roig et al., 2018). For instance, women have higher risk of transition to disability in five countries (Spain, Italy, The Netherlands, Austria and Belgium), also considering the competing risk of death. However, this risk remains higher for women only in Spain, Italy and Belgium in the model that considers dependency measured by

difficulties in BADLs. However, the results in Belgium were inconsistent with different model specifications.

The inconsistency of the results between disability, measured by the difficulties in performing BADLs and/or IADLs, and dependency, measured by the difficulties in performing BADLs are in line with the literature. Previous analyses reported sex differences in difficulties to perform IADLs but not BADLs (Crimmins et al., 2011). As already suggested by Millán-Calenti and co-authors (2010), sex differences in performing IADLs could be explained by the different roles of women and men in domestic tasks, as IADLs like preparing a hot meal or going for shopping are mostly done by women, and hence may declared higher difficulties in performing them.

On the other hand, no sex differences in the risk of transition to dependency appear in most countries (The Netherlands, Austria, Belgium, France, Germany, Sweden, Denmark and Switzerland), suggesting that the 'male-female survival-health paradox' do not hold for dependency state. As already argued, difficulties in BADLs can be considered an indicator of care dependence and thus of a state in which individuals need help from others (Rodríguez-Sampayo et al., 2011). Sex differences emerged consistently for all specifications in the transition to dependency, measured by difficulties in performing BADLs, only in Italy and Spain. In Belgium, the results were not robust to different model specifications, so sex differences in the transition to dependency in this country cannot be ensured. Despite this, the results for Spain and Italy are concerning. In these countries, universal care systems are absent or partially developed and their cultural norms have a high level of family obligations to care needs, which usually falls in women unpaid work (Geerts and Van den Bosch, 2012). Therefore, care policies should take special account of sex differences in order to decrease the burden of care on (informal) family caregivers.

On the other hand, current results allowed to understand how the probability of transition to disability changes with increasing age across countries. This probability increases until 70 years old for all countries and both disability measures. Additionally, in most countries the LE suggest that women live with difficulties and may require daily help from others for longer than men.

The current results are not without limitations. Firstly, the approximation of older adults' dependence is through a proxy measure, due to the lack of information about the need for help to perform ADLs in SHARE data. Thus, this results can only contribute to the understanding of dependence that is generated by the person's functional difficulty in performing daily activities. However, with the available data it is not possible to inform about other dimensions linked to dependence and the need for help from others. For instance, dimensions related to mental health, depressive symptoms, among others that may affect the dependence state of older individuals beyond their functional disability. It would be imperative that surveys of longitudinal studies of aging consider incorporating questions about the need for help in ADLs in order to be more accurate in future analyses of dependence. Second, the disability measures are based on self-reported and although there are good for approximating this condition, it would be desirable to complement them with other objective measures (Bravell et al., 2011; Duim and Ferrer, 2017).

Transitions to disability, dependency and death are affected by age, sex, educational attainment and self-perceived health status. Heterogeneity across European countries in terms of sex differences in transitions to disability and dependency was evident, although not as widespread when we proxy dependence on the basis of difficulties in performing BADLs. However, there were some countries (Italy and Spain) with sex differences in dependency and with their cultural and institutional contexts gender-sensitive care policies are crucial.

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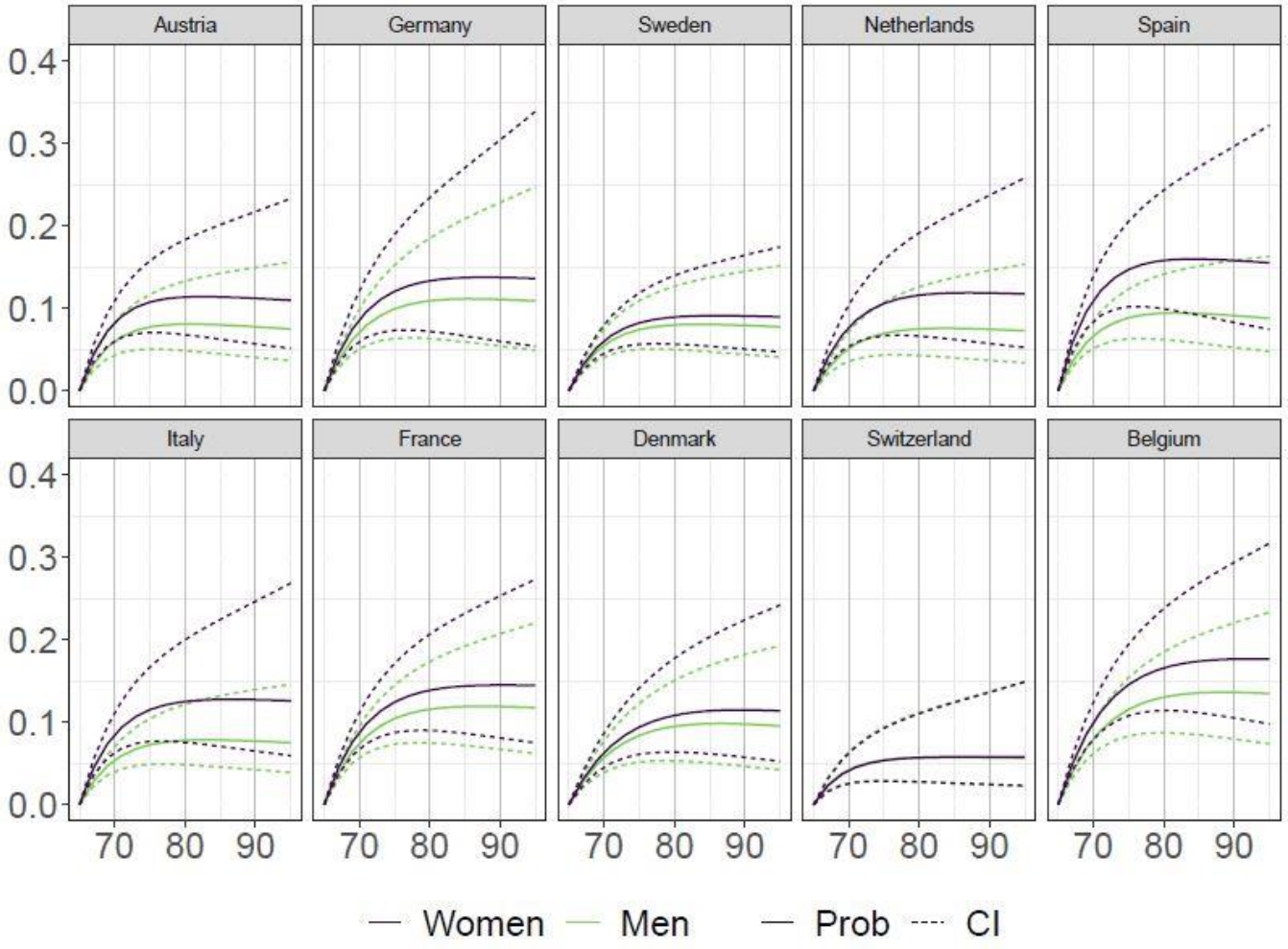
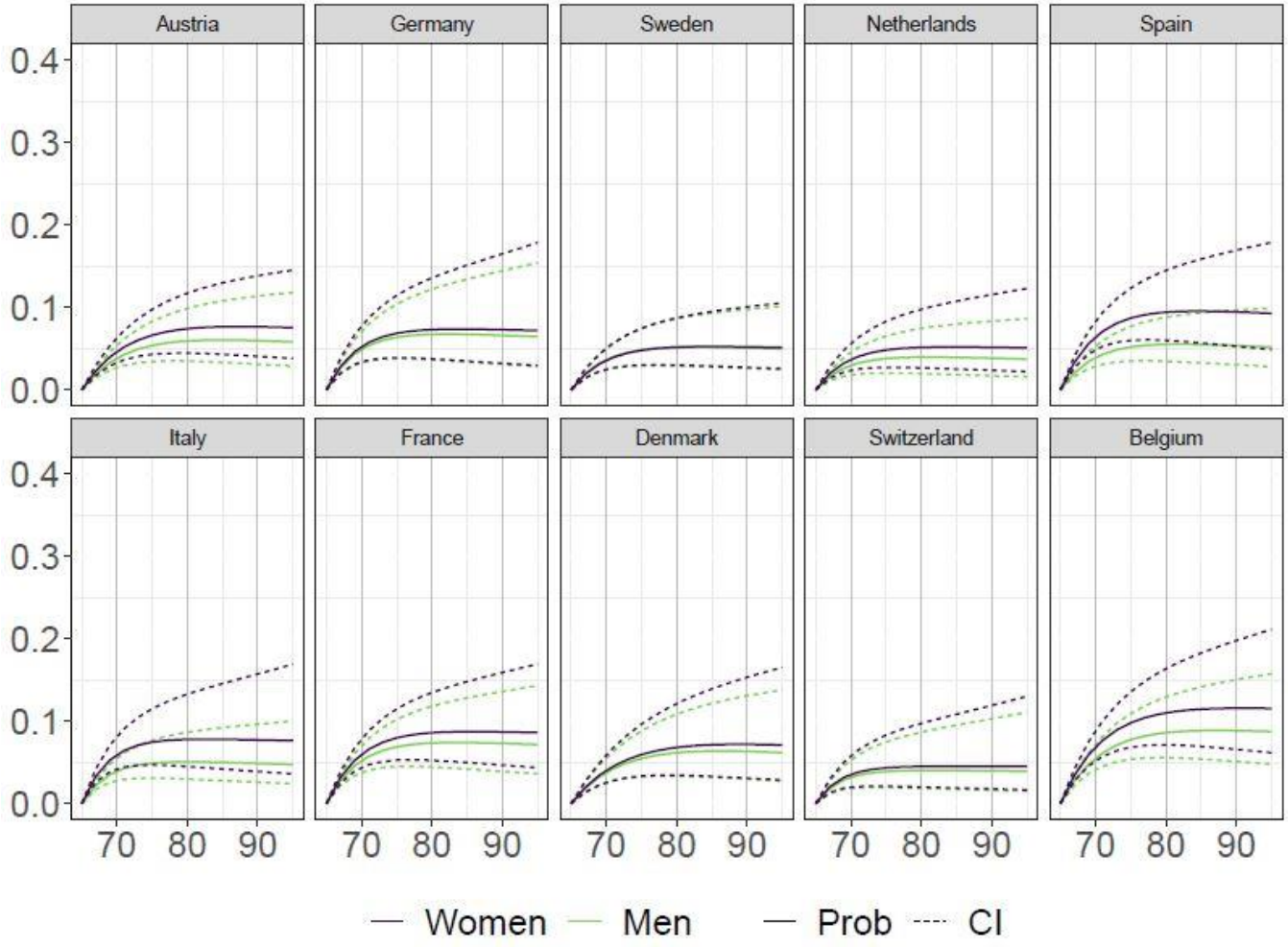
Supplementary material

Figure S1. Probability of transition to disability state with age for women and men by country



Notes: D state is a disability state, and was determined when the individual had difficulties in at least one BADLs and/or IADLs.

Figure S2. Probability of transition to dependency state with age for women and men by country



Notes: D state is a dependency state, and was determined when the individual had difficulties in at least one BADLs.

Table S1. Hazard ratio and 95% confidence intervals for the effect of sex on transitions by country

	Transition ND - D	
Country	Diff. B&IADL	Diff. BADL
Austria	1.342* (1.073-1.678)	1.128 (0.873-1.456)
Germany	1.136 (0.876-1.474)	1.032 (0.768-1.386)
Sweden	1.109 (0.902-1.364)	0.989 (0.772-1.268)
The Netherlands	1.486* (1.154-1.913)*	1.269 (0.898-1.792)
Spain	1.668* (1.401-1.986)	1.608* (1.318-1.963)
Italy	1.558* (1.279-1.897)	1.493* (1.199-1.858)
France	1.119 (0.941-1.331)	1.075 (0.880-1.312)
Denmark	1.040 (0.809-1.338)	1.025 (0.756-1.391)
Switzerland	0.928 (0.694-1.240)	1.097 (0.768-1.566)
Belgium	1.233* (1.043-1.457)	1.218* (1.006,1.475)

Notes: The table shows the effect of being female on the risk of transitioning in the model that includes age, sex, and educational attainment. Disability state was determined when the individual had difficulties in at least one BADLs and/or IADLs. Dependency state was determined as a proxy, when the individual had difficulties in at least one BADL. Abbreviations: ND: No Disability; D: Disability; Diff. B&IADL: Difficulties in BADLs and/or IADLs; Diff. BADL: Difficulties in BADLs; HR, hazard ratio; BADL: Basic Activities of Daily Living; IADL: Instrumental Activities of Daily Living. * 5% significant ratio.

Table S2. Hazard ratio and 95% confidence intervals for the effect of sex on transitions by country

	Transition ND - D	
Country	Diff. B&IADL	Diff. BADL
Austria	1.321* (1.056-1.654)	1.095 (0.846-1.418)
Germany	1.154 (0.891-1.495)	1.036 (0.773-1.390)
Sweden	1.037 (0.841-1.279)	0.926 (0.719-1.193)
The Netherlands	1.518* (1.175-1.96)	1.246 (0.877-1.771)
Spain	1.652* (1.387-1.969)	1.588* (1.301-1.939)
Italy	1.521* (1.247-1.855)	1.452* (1.166-1.808)
France	1.133 (0.952-1.348)	1.059 (0.867-1.294)
Denmark	1.028 (0.796-1.326)	1.005 (0.738-1.369)
Switzerland	0.889 (0.666-1.188)	1.074 (0.753-1.533)
Belgium	1.217* (1.030-1.439)*	1.202 (0.993-1.456)

Notes: The table shows the effect of being female on the risk of transitioning in the model that includes age, sex, educational attainment, and self-perceived health. Disability state was determined when the individual had difficulties in at least one BADLs and/or IADLs. Dependency state was determined as a proxy, when the individual had difficulties in at least one BADL. Abbreviations: ND: No Disability; D: Disability; Diff. B&IADL: Difficulties in BADLs and/or IADLs; Diff. BADL: Difficulties in BADLs; HR, hazard ratio; BADL: Basic Activities of Daily Living; IADL: Instrumental Activities of Daily Living. * 5% significant ratio.

Chapter 2: Dependency change with aging and associated factors in Uruguay: a cohort study

Abstract

Objectives: To assess the heterogeneity of transitions toward dependency in older adults and to explore the robustness of results to different operationalizations of dependency. **Method:** Using data from people aged 60 years and older from a national representative study in Uruguay (*Encuesta Longitudinal de Protección Social*, N= 5071), we fitted multinomial regressions adjusted by sociodemographic and health characteristics to model transitions into dependency and death. We used a harder operationalization with basic activities of daily living (Katz-dependency) and Comprehensive-dependency with basic, instrumental, and advanced activities. **Results:** Increasing age (RRR = 1.08, CI = [1.05; 1.12], p< .001) and having comorbidities (RRR = 2.16, CI = [1.31; 3.57], p= .003) increased the risk of transition from nondependent to dependent using Katz-dependency. Women with at least two chronic conditions have increased risk of Comprehensive-dependency (RRR = 1.79, CI = [1.15; 2.80], p=.010). **Discussion:** Inconsistencies in findings emerged when evaluating transitions into dependency with the different measures, which may have social care implications.

Keywords: Dependency; Activities of Daily Living; Older Adults; Uruguay

JEL code: I10; I31, J14

Background

Older populations exhibit higher prevalence of chronic diseases, disability and dependency, and as a consequence of these higher prevalences, national social security and health care systems are usually placed under stress (At et al., 2015; Prina et al., 2020; Sousa et al., 2010). With increasing age, the risk of dependency tends to increase, as functional or mental impairments result from declines in health. Yet, the need for daily help or care of older adults living in the community has been shown to be heterogeneous and depend on socio-demographic characteristics such as age, sex, or education (At et al., 2015; Sousa et al., 2009, 2010).

Demographic changes experienced in the past decades in low- and middle-income countries have increased the older segments of the population, stressing the social security, healthcare system and also could be leading to a deterioration in the quality of life of the older population. For instance, in Latin American countries, the share of older people has been increasing since 1990 and is expected to double between 2019 and 2050 (United Nations, 2020). Uruguay, a country with a population of 3.4 million, exhibits the oldest population in Latin America, with 19 per cent of this population aged 60 years or older in 2015 (Rofman et al., 2016). Furthermore, it has been reported that Uruguay began its demographic transition earlier than other Latin American countries (Rofman et al., 2016). Yet, despite being the country with the oldest population in Latin America, the need for help, care or support of older Uruguayan adults, and its changes over time, have not been studied widely.

Developed countries have already gone through these demographic changes and have therefore planned, implemented and reformed their policies to deal with problems associated with dependency of the older population (Matus-López, 2015). However, only some Latin American countries have implemented measures to address these problems, in particular, the ones

associated with increased dependency to care or support (Galiani et al., 2017; Matus-López, 2015; Matus-López and Rodríguez-Modroño, 2014). Uruguay stands out among Latin American countries due to the implementation of a new Long-Term Care (LTC) program within the framework of the National Care System (NCS) initiated in 2015. Among its objectives, the NCS aims to promote the development of autonomy of dependent older adults, providing them care through services and assistance (Matus-Lopez and Cid Pedraza, 2016).

The World Health Organization (WHO) defined disability as an umbrella term for impairments, activity limitations, and participation restrictions which denotes the negative aspects of the interaction between an individual with a health condition and that individual's environmental and personal factors (WHO, 2001). Dependency, a multidimensional construct that could refer to functional, psychosocial and supportive dimensions and that could also include an economic dimension (Edjolo et al., 2016; Rely et al., 2020), is defined as the need for human help or care beyond that habitually required by a healthy adult (Harwood et al., 2004).

Although the definitions of disability and dependency are clear, there is no consensus on how to operationalize dependency. For instance, in large national representative studies with a multidisciplinary scope such as *The Cognitive Function and Ageing Study* (CFAS) from England and *The Survey of Health, Ageing and Retirement in Europe* (SHARE), different operationalizations were used. Additionally, these differences in the operationalization were evidenced in previous analysis for Latin American countries (Monteverde et al., 2016). Specifically, while in the British study dependency was operationalized using the interval measure, which is based on the lapsed time between periods when participants might require help (Kingston et al., 2017), in SHARE and for Latin American countries it was operationalized counting the limitations in daily activities (Monteverde et al., 2016; Rodríguez-Sampayo et al.,

2011). Moreover, it has been suggested that to adequately operationalize dependency, in addition to the actual limitations that individuals may experience, it is also necessary to consider information about the daily need for help (Albarrán Lozano et al., 2009; Edjolo et al., 2016; Harwood et al., 2004; Prina et al., 2020). Hence, it could be argued that it is possible to operationalize dependency using information about the need for assistance in performing Activities of Daily Living (ADLs). So, in sum, to assess dependency information about the need for human help will be used, in addition to information on the limitations to perform daily activities.

Much of the literature on disability and functional status of older adults have used the Basic Activities of Daily Living (BADLs) that includes activities such as bathing, dressing, toileting, transferring, continence, and feeding (Katz et al., 1963). Later these activities were extended to include Instrumental Activities of Daily Living (IADLs) such as the ability to use the telephone, shopping, housekeeping, among others (Lawton and Brody, 1969). Recently, Advanced Activities of Daily Living (AADLs), that includes social and community participation, communicating and making decisions, are also considered (WHO & WB, 2011).

Including different types of activities and its various combinations can inform about different aspects of dependency experienced by older adults (Millán-Calenti et al., 2010). For instance, a harder operationalization of dependency would consider only BADLs whilst more advanced and comprehensive assessment of the construct could also consider IADLs and AADLs.

Previous analyses have reported that trajectories towards dependency are characterized by a first need for help in IADLs and then an overlapping need for help in BADLs and IADLs (Edjolo et al., 2016).

The ‘male-female health-survival paradox’ that postulates that women have longer life expectancies but they live in poorer health, is a well-documented phenomenon (Austad, 2006; Bora and Saikia, 2015; Cameron et al., 2010). For instance, a national representative study for England concludes that the proportion of independent older people will increase in the next 20 years but men will be successively more independent than women (Kingston et al., 2017). Using data from several Latin American countries, it has been reported that women spend a longer time with difficulties than men (Prina et al., 2020). The patterns of dependency by sex could also be affected by men and women’s different roles in household activities, and a comparison between different cultures and contexts could provide new insights into patterns of heterogeneity (Millán-Calenti et al., 2010). Sex differences may be relevant to inform the actions to be taken to ensure quality of life of older people despite their difficulties.

In turn, educational level, socioeconomic conditions, physical or functional impairments, and the existence of co-morbidities are risk factors for disability and dependency (Mayston et al., 2014; Prina et al., 2020), although more evidence is needed to understand the dynamics of disability and dependency (Prina et al., 2020).

The different assessment of dependency may provide complementary perspectives of the problem that informs policy design. For instance, to ensure that care or assistance meet needs of dependent older people, it is relevant to analyze differences in the type of activities that individuals will need help with. Previous research has not examined transitions to dependency, and death or the robustness of results to different operationalizations of dependency. A better understanding of dependency, its changes with increasing age including death and its associated factors is critical to inform care policies designed to improve quality of life of older people living in the community and their families.

In this first study of dependency of the population of older Uruguayans, we aim to generate knowledge about their dependency with increasing age, using data from a nationally representative cohort study and modeling transitions including death. We address the following questions:

1) Do transitions towards dependency vary by age, sex and education after controlling for co-morbidities and impairment in the population of older adults in Uruguay?
2) Are these transitions sensitive to the measures of dependency considered? Is there heterogeneity by age, sex, education, co-morbidities and impairments?

Methods

Data

We used data from the *Encuesta Longitudinal de Protección Social* (ELPS) for Uruguay. Baseline data were collected between 2012 and 2013, and the follow-up assessments between 2015 and 2016.

This survey is self-reported and representative of the national population of individuals aged 14 years old or older. Participants were asked basic questions about their sociodemographic characteristics and health, in addition to questions about whether they received government benefits, their employment history, social security, heritage and household composition. Specifically, participants were asked their age, sex and the highest level of education completed. They were asked whether they had hearing or sight difficulties, and were asked if they had been diagnosed with any of the following conditions: asthma, emphysema, arthrosis or arthritis, tendinitis, rheumatism, hypertension, diabetes, osteoporosis, kidney failure, cardiac problems, spine problems, anemia, cancer and HIV.

For this study, we considered individuals aged 60 years old and older at baseline. Of the 6197 individuals in this age group surveyed at baseline, 1716 (28%) were not included in the follow up wave (11% died, 1% moved to a nursing home and 16% were untraceable). Hence, the analytical sample included 4462 individuals with complete data in both waves and 609 individuals with complete data in the first wave who died before the second wave, totalizing 5071 cases. For further information about the design of the baseline and follow-up data collection waves of the ELPS see BPS (2015).

For the purposes of our analyses, we derived a series of dummy variables to account for differences in education (1= highest educational level completed is primary school or less, 0=otherwise) and sex (1= Female, 0= Male). Dummy variables were also created to indicate the presence of physical health conditions or difficulties. Specifically, a series of independent dummy variables were derived indicating whether an individual had difficulties with their sight (1= have difficulties, 0= otherwise); had hearing difficulties (1= have difficulties, 0= otherwise), had two or more chronic diseases (1= have two or more chronic conditions, 0= have less than two chronic conditions). Age was measured in years.

Dependency measures

We measured dependency in two different ways. First, we defined an indicator variable that took the value of 1 if an individual needed help on a regular basis with at least one of the following activities: eating, dressing, personal care activities (toothbrush, to comb or face washing), displacing inside home, or using the restroom (Katz et al., 1963). If an individual needed help with at least one of these activities on a regular basis (i.e. declared the need for help "Sometimes", "Many times" or "Always"), we classified the individual as dependent (Katz-

dependency from now on). For the analysis of the Katz-dependency we also considered the number of activities in which the person needs help from these five.

Second, we defined dependency using data on the frequency of need for help in any of the activities available in the ELPS study which includes basic, instrumental and advanced activities (Comprehensive-dependency from now on). This approach adds to the five previous activities included in the definition of the Katz-dependency measure the following activities: avoiding health risk (e.g. taking medications), changing/maintaining position, displacing outside home, performing housework, participating in social life and communicating. We also employ the number of activities in which the person needs help from these eleven for the analysis of Comprehensive-dependency and its associated factors.

The use of these two operationalizations of dependency allows us to assess dependency with a harder operationalization (Katz-dependency) that considers only BADLs, and with a more comprehensive assessment (Comprehensive-dependency) that considers also the IADLs and AADLs available in the survey, and therefore, to perform a sensitivity analysis of results to these two different measures.

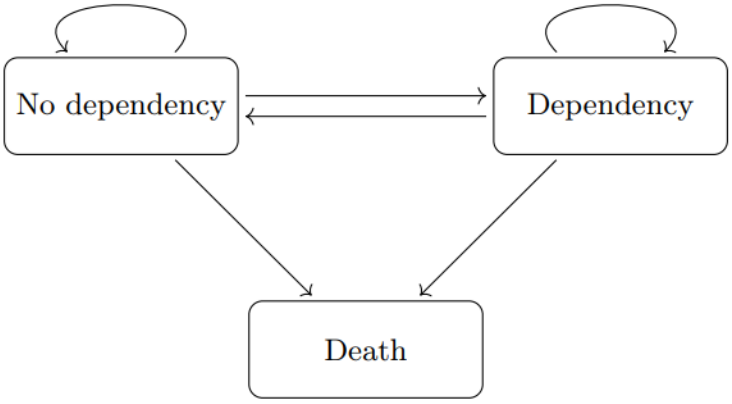
Statistical Analysis

To analyze transitions into dependency we used multinomial logistic regressions to investigate the association between socio-demographic characteristics, co-morbidities and other limitations with transitions into dependency states and death.

In the first wave there are two possible states: no dependency (ND) and dependency (D), while in the second wave, individuals may have died, and therefore, the additional deceased state (Dth) was considered (See Figure 1 for a pictorial representation of the model). In our

multinomial model staying non-dependent (ND-ND) is the reference category, interpreting the coefficients relative to this transition.

Figure 1. Three state model of transitions into dependency states and death



We were interested in the association of the different factors with the odds of experiencing any transition. Henceforth, we look for the Relative Risk Ratio (RRR) of a given transition, relative to the risk of being non-dependent in both periods (ND-ND). As an example, suppose we were interested in the differences between men and women in the risk of transition ND-D, given a set of control variables X. The RRR representing the risk ratio women have relative to men, of transition ND-D can be written as:

$$RRR = \frac{P(transition = ND - D|X, woman = 1)/P(transition = ND - ND|X, woman = 1)}{P(transition = ND - D|X, woman = 0)/P(transition = ND - ND|X, woman = 0)}$$

We further investigated factors associated with both measures of dependency at baseline considering a multivariate perspective. We ran Ordinary Least Squares (OLS) to evaluate the association of factors with the number of activities requiring help at baseline, and logistic regressions to inquire on factors associated with the probability of being dependent.

The multivariate models were adjusted simultaneously by age, sex, education, presence of two or more chronic conditions, visual and hearing difficulties. In addition, we included interactions of sex with age and with the presence of two or more chronic conditions in order to reflect the well-known 'male-female survival health-paradox' documented in previous literature.

Individuals who died before the second wave were included in the regressions. Besides, there was no information that allowed us to determine the state at follow up of those untraceable in the second wave (995 cases), hence to analyze if they were different from those with complete data, we checked for differences in the mean of variables between lost individuals and those present in both waves.

All the statistical analyses were done first with the hardest measure of dependency (Katz-dependency) and then considering the more comprehensive measure of dependency (Comprehensive-dependency) and results were compared. Finally, we ran all analyses using STATA 13.

Results

Descriptive Statistics

Table 1 presents descriptive baseline statistics for the sample analyzed. The average age of individuals in the sample was 72 (SD=8.2) years old and 61% of the sample were women. Almost 60% of the individuals reported that primary school was the highest educational level completed. Sight difficulties (7%) were more prevalent than hearing difficulties (2%), and 42% of individuals had at least two chronic diseases.

Table 1. Descriptive statistics of analytical sample at baseline (N=5071)

Age	Mean (SD)	*Sex*	N (%)
Age (years)	71.9 (8.2)	Female	3074 (60.6)
Age ranges	N (%)	Male	1997 (39.4)
60-64	1104 (21.8)	*Chronic Conditions (CC)*	N (%)
65-69	1153 (22.7)	Fewer than two CC	2917 (57.5)
70-74	984 (19.4)	Two or more CC	2154 (42.5)
75-79	797 (15.7)	*Sight difficulties*	N (%)
80-84	634 (12.5)	Sight difficulties (Yes)	365 (7.2)
85 or more	399 (7.9)	Sight difficulties (No)	4706 (92.8)
Education	N (%)	*Hearing difficulties*	N (%)
Primary school or less (Yes)	3011 (59.4)	Hearing difficulties (Yes)	105 (2.1)
More than primary school (Yes)	2060 (40.6)	Hearing difficulties (No)	4966 (97.9)

Table 2 presents the descriptive statistics for the dependency measures at baseline, and the distribution of the sample for transitions among dependency states and death. Individuals classified as Katz-dependent at baseline are 4.4%, and this percentage almost doubles when using the Comprehensive-dependency measure (8.1%). On average individuals required assistance in 0.09 (SD=0.5) of the five Katz activities, while this number rises to 0.25 (SD=1.1) when considering the eleven activities of the comprehensive measure.

The analytical sample did not differ from individuals not followed in the second wave in terms of age (t-test, p=0.18), sex (t-test, p=0.68), education (t-test, p=0.13), hearing impairments (t-

test, p=0.30), number of chronic conditions (t-test, p=0.47), Katz-dependency status (t-test, p=0.89) or Comprehensive-dependency status (t-test, p=0.21). However, there are difference in terms of visual impairments (t-test, p=0.05). These results suggest that there is no selection in the missing data.

Table 2. Descriptive statistics of dependency measures of analytical sample at baseline (N=5071)

Number and percentage of people requiring help in each activities			
Katz activities	N (%)	*Other activities*	N (%)
Eating	32 (0.6)	Avoiding health risks	52 (1.0)
Dressing	116 (2.3)	Changing/maintaining position	68 (1.3)
Personal care	114 (2.2)	Displacing outside house	269 (5.3)
Displacing inside house	121 (2.3)	Performing housework	231 (4.6)
Using the restroom	92 (1.8)	Participating in social life	108 (2.1)
		Communicating	61 (1.2)
Katz-Dependency	N (%)	*Comprehensive-Dependency*	N (%)
Katz-Dependent (Yes)	224 (4.4)	Comprehensive-Dependent (Yes)	409 (8.1)
Katz-Dependent (No)	4847 (95.6)	Comprehensive-Dependent (No)	4662 (91.9)
Number of activities requiring help from:	Mean (SD)	*Number of activities requiring help from:*	Mean (SD)
5 activities of Katz	0.09 (0.5)	11 activities of Comprehensive	0.25 (1.1)

Transitions			
Katz-dependency	N (%)	*Comprehensive-dependency*	N (%)
ND-ND	4061 (80.1)	ND-ND	3650 (72.0)
ND-D	244 (4.8)	ND-D	527 (10.4)
ND-Dth	542 (10.7)	ND-Dth	485 (9.6)
D-ND	61 (1.2)	D-ND	90 (1.8)
D-D	78 (1.5)	D-D	177 (3.5)
D-Dth	85 (1.7)	D-Dth	142 (2.8)

Notes: ND-D: Non-dependent to Dependent; ND-Dth: Non-dependent to Death; D-ND: Dependent to Non-dependent; D-D; Dependent to Dependent; D-Dth: Dependent to Death.

Risk factors of dependency using the Katz-dependency measure

The results show (See Figure 2) increasing age is associated with a higher number of Katz activities requiring help on average (β=0.004, SE=0.001, p=0.006). Also, the presence of at least two chronic conditions (β=0.080, SE=0.025, p=0.001) and having sight difficulties (β=0.156, SE=0.028, p<0.001) increase this number. Women have a lower mean number of activities that requires help at baseline (β=-0.509, SE=0.129, p<0.001) but, since the interaction of age and sex is positive and significant (β=0.007, SE=0.002, p<0.001), increasing age increases the mean number of activities requiring help even more for women than for men. Although having hearing difficulties (β=0.090, SE=0.050, p=0.074) or low educational level (β=0.027, SE=0.015, p=0.072) may have a positive association with the activities requiring help, the coefficients do not reach traditional statistical significance. Finally, results didn't show

significant association of the interaction between having two or more chronic conditions and sex (β=-0.028, SE=0.031, p=0.352).

Turning to the risk of being Katz-dependent at baseline, results show increasing age (OR=1.07, CI=[1.04;1.11], p<0.001), having two or more chronic conditions (OR=3.06, CI=[1.79;5.24], p<0.001), having sight difficulties (OR=3.06, CI=[1.79;5.24], p<0.001) and a lower educational level (OR=1.61, CI=[1.16;2.24], p=0.005) are associated with a higher risk of being Katz-dependent. However, there are no differences in the risk of being Katz-dependent between women and men (OR=0.55, CI=[0.03;10,15], p=0.690) either the interaction of age with sex (OR=1.02, CI=[0.98;1.05], p=0.431) nor having two or more chronic conditions with sex (OR=0.66, CI=[0.35;1.26], p=0.209) present statistically differences. These results are shown in Figure 2 and in the Supplementary material, Table S1.

Table 3 panel (a) shows the results of the multinomial logistic regression using the Katz-dependency measure to define a dependent state of the individual. As individuals age, the results show that the relative risk of each transition is greater than that of the transition of being non-dependent in both waves with the exception of remaining in a dependent state, where the estimate was not significant. Thus, we could expect that per additional year of older age individuals are more likely to move from a non-dependent towards dependent state, relative to remain non-dependent (RRR=1.08, CI=[1.05;1.12], p<0.001). Having at least two chronic conditions increases the relative risk of moving from non-dependent state towards dependent (RRR=2.16, CI=[1.31;3.57], p=0.003) and from dependent to death (RRR=5.35, CI=[2.30;12.44], p<0.001). Women also have a lower relative risk of transition to death from non-dependent state (RRR=0.05, CI=[0.01;0.31], p=0.001). Having a lower educational level increases the risk of transition to death from a non-dependent state (RRR=1.43, CI=[1.16;1.76],

p=0.001) and from dependent state (RRR=2.00, CI=[1.11;3.58], p=0.020), relative to the risk of remaining non-dependent in both waves. Finally, having sight difficulties increases the risk of transition from dependent to death (RRR=3.76, CI=[2.22;6.34], p<0.001), recover from a state of dependency (RRR=4.24, CI=[2.34;7.69], p<0.001), and remain dependent (RRR=2.55, CI=[1.39;4.65], p=0.002), relative to stay non-dependent in both waves.

In sum, increasing age and having two or more chronic conditions were found to be the factors associated with a higher risk of transition from a non-dependent to a dependent state, relative to remain non-dependent with the Katz-dependency measure.

Risk factors of dependency using the Comprehensive-dependency measure

The frequency of each transition was sensitive to the dependency measure (see Table 1). While 4.8 % of the sample transitioned from a non-dependent to a dependent state when dependency was operationalized using Katz measure, this percentage has a two fold increase (10.4%) when considering the Comprehensive-dependency measure. However, for both measures the permanence in a non-dependent state is the most frequent.

In terms of dependency at baseline, the results for the Comprehensive-dependency measure are similar to the results obtained for Katz-dependency measure. The differences are that for the total of activities, the effects sizes are greater than for Katz's activities and that hearing difficulties increased the risk of being Comprehensive-dependent, while it was not associated with being Katz-dependent (See Figure 2 and Table S1 in Supplementary material).

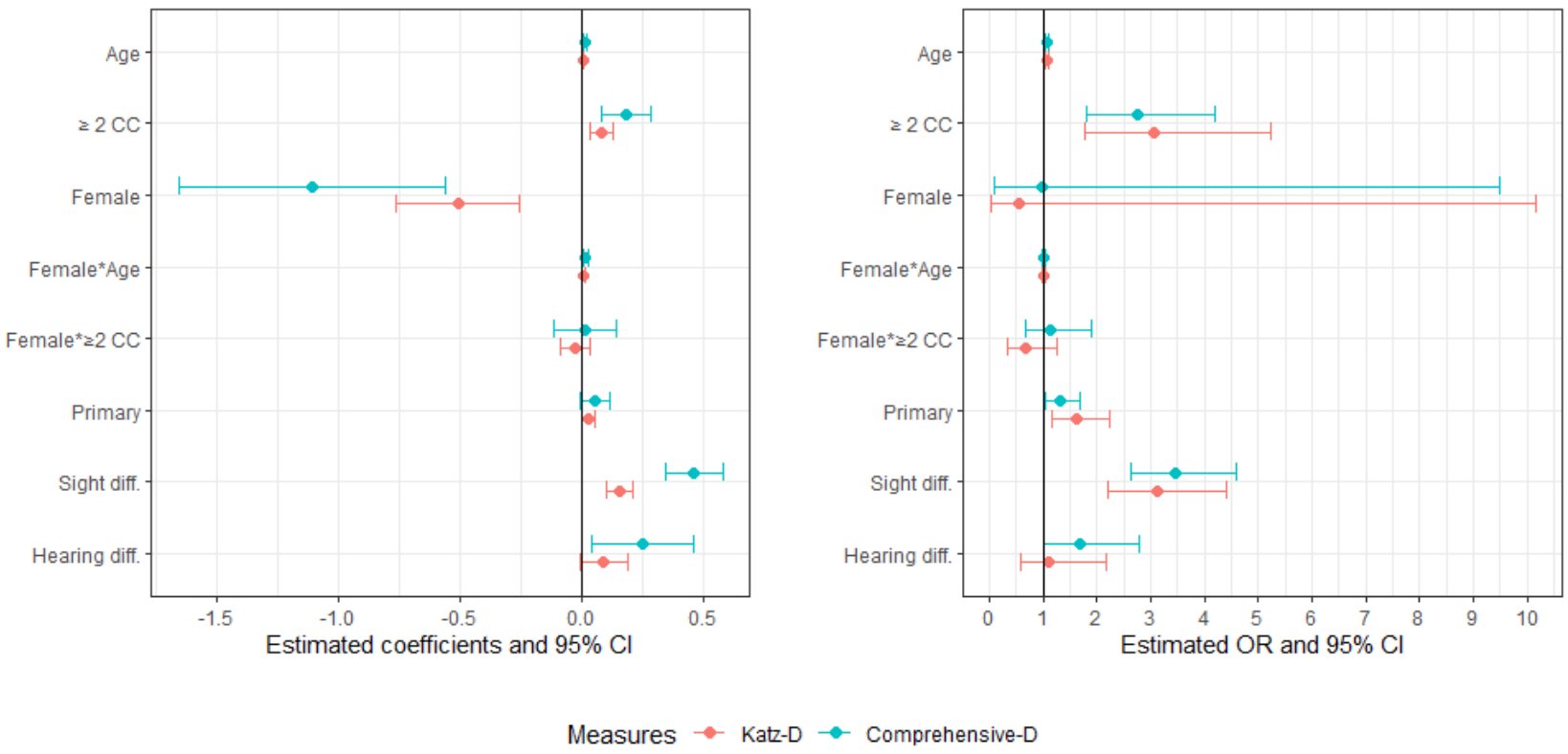
In addition, when we use the Comprehensive-dependency measure rather than the Katz-dependency measure, the results show inconsistencies with respect to the factors associated with risk of transitions into dependent and non-dependent states and death (see Table 2). While the effect of age does not change in direction and magnitude when the different measures are used,

having two or more chronic conditions was not found to be significantly associated with the risk of becoming Comprehensive-dependent relative to remain non-dependent, contrary to the previous significant result when the Katz-dependency measure was used. In addition, having a low educational level (RRR=1.33, CI=[1.08;1.63], p=0.010) and sight difficulties (RRR=1.86, CI=[1.34;2.58], p=0.000) were associated with a greater risk of transiting to a Comprehensive-dependent state, relatively to remain non-dependent. More importantly, results show that the interaction between being female and having at least two chronic conditions increases the risk of becoming Comprehensive-dependent (RRR=1.79, CI=[1.15;2.80], p=0.010). For instance, we could expect that a woman with two or more chronic conditions has a risk 1.79 times higher of moving from non-dependent to Comprehensive-dependent relative to stay non-dependent.

Figure 2. Associated factors to dependency at baseline

(a) Number of activities

(b) Dependent (Yes/No)



Panel (a): OLS for number of activities requiring help. Katz-D counts help in five activities and Comprehensive-D in eleven activities. Panel (b): logistic regression for dependent state at baseline. Katz-D defines dependent if required help in at least one activity of Katz-dependency measure and Comprehensive-D defines dependent if required help in at least one activity of the Comprehensive-dependency measure. Abbreviations: CC, Chronic conditions. CI, Confidence Interval. OR, Odds Ratio.

Table 3. Relative risk ratios for transitions to dependency and death. Base transition ND-ND.

	(a) Katz-dependency					(b) Comprehensive-dependency				
	ND-D	ND-Dth	D-ND	D-D	D-Dth	ND-D	ND-Dth	D-ND	D-D	D-Dth
Age	1.08***	1.08***	1.11**	1.04	1.14***	1.09***	1.09***	1.05*	1.08***	1.15***
	(1.05;	(1.06;	(1.02;	(0.98;	(1.09;	(1.07;	(1.07;	(0.99;	(1.03;	(1.10;
	1.12)	1.10)	1.20)	1.10)	1.20)	1.12)	1.11)	1.11)	1.12)	1.19)
≥ 2 CC	2.16***	1.22	3.26*	2.03	5.35***	1.30	1.16	2.21*	2.43**	3.90***
	(1.31;	(0.92;	(0.91;	(0.86;	(2.30;	(0.89;	(0.87;	(0.90;	(1.23;	(2.05;
	3.57)	1.61)	11.72)	4.75)	12.44)	1.91)	1.55)	5.39)	4.80)	7.40)
Female	2.87	0.05***	211.61	0.01**	0.05	3.12	0.06***	4.31	0.37	0.01**
	(0.18;	(0.01;	(0.28;	(0.00;	(0.00;	(0.41;	(0.01;	(0.04;	(0.01;	(0.00;
	45.04)	0.31)	159516)	0.71)	7.84)	23.54)	0.43)	517.30)	14.07)	0.62)
Female*Age	0.99	1.03**	0.94	1.07**	1.04	0.99	1.03**	0.98	1.02	1.06**
	(0.95;	(1.01;	(0.87;	(1.01;	(0.98;	(0.96;	(1.00;	(0.92;	(0.97;	(1.01;
	1.02)	1.05)	1.03)	1.14)	1.11)	1.02)	1.05)	1.05)	1.07)	1.12)
Female*≥2 CC	1.31	1.09	0.96	1.10	0.36**	1.79**	1.15	2.24	1.66	0.83

	(0.72;	(0.74;	(0.23;	(0.39;	(0.13;	(1.15;	(0.76;	(0.76;	(0.75;	(0.37;
	2.41)	1.60)	4.05)	3.07)	0.99)	2.80)	1.73)	6.60)	3.66)	1.84)
Primary	1.20	1.43***	1.57	1.61*	2.00**	1.33***	1.43***	1.18	1.32	2.02***
	(0.90;	(1.16;	(0.88;	(0.95;	(1.11;	(1.08;	(1.15;	(0.76;	(0.94;	(1.28;
	1.59)	1.76)	2.70)	2.73)	3.58)	1.63)	1.78)	1.85)	1.85)	3.19)
Sight diff.	1.43	1.35*	4.24***	2.55***	3.76***	1.86***	1.42*	4.80***	3.86***	4.32***
	(0.92;	(0.97;	(2.34;	(1.39;	(2.22;	(1.34;	(0.98;	(0.98;	(2.57;	(2.77;
	2.20)	1.88)	7.69)	4.65)	6.34)	2.58)	2.08)	2.08)	5.82)	6.74)
Hearing diff	0.89	1.57*	0.94	1.41	1.29	1.52	1.63	2.96**	1.42	2.28**
	(0.37;	(0.94;	(0.22;	(0.48;	(0.51;	(0.83;	(0.90;	(0.90;	(0.60;	(1.09;
	2.14)	2.63)	4.10)	4.16)	3.29)	2.78)	2.97)	2.97)	3.36)	4.74)
N	5,071	5,071	5,071	5,071	5,071	5,071	5,071	5,071	5,071	5,071

Notes: 95% confidence intervals in parentheses; *** p<0.01, ** p<0.05, * p<0.1

ND-ND: Non-dependent to Non-dependent; ND-D: Non-dependent to Dependent; ND-Dth: Non-dependent to Death;

D-ND: Dependent to Non-dependent; D-D; Dependent to Dependent; D-Dth: Dependent to Death. CC: Chronic conditions.

Sensitivity analyses and additional analyses

We performed two sensitivity analyses to study the robustness of our results. First, we changed the Katz-dependency measure, replacing the activity of "Displacing inside home" with "Changing/maintaining position". Second, we analyzed the subsample of individuals who responded the survey by themselves, which implies a loss of 3% of the analytical sample (the subsample corresponds to 4468 cases). The results are in the Supplementary material, Tables S2-S5.

Further, we performed additional analyses which are also included in the Supplementary material. We have fitted a series of multinomial logistic models adding the covariates one at a time and using interaction terms to capture the 'male-female health-survival paradox'. Also, we have added a dummy variable to indicate whether the person lives alone or not ("Lives alone" =1, the person lives alone; "Lives alone" =0, otherwise). For the sake of brevity, we have reported in the Supplementary material, Tables S6-S7, only the relative risk ratios for the transition ND-D, for both dependency operationalizations (Katz- and Comprehensive-dependency). Finally, we have considered the net household income of the last month (in logs) and included it as a covariate in the model. However, as 20% of the data on income is missing, the number of observations for models including income as a covariate, is 4162. Hence, we added an additional estimation of the multinomial logistic regression with this subsample and the results are reported in Table S8 in the Supplementary material.

Discussion

Our work reports the first investigation about dependency and its dynamics for older adults in Uruguay using data from a national representative study. The main aims of the current work were to assess the heterogeneity of transitions towards dependency by socio-demographic

characteristics in the population of older adults and to explore the sensitivity to different measures of dependency. In our analyses, heterogeneity of transitions towards dependency emerged, and results showed inconsistencies when evaluating these transitions with different measures.

Firstly, we showed that it is more likely to transition to dependency when a comprehensive measure of the construct is used. Although, this could be due to the greater number of activities in the measure, it also may be related to the different type of activities included. As previously reported in the literature, IADLs are the first in which people become dependent, and older people tend to have, on average, less difficulty with BADLs than with IADLs (Carmona-Torres et al., 2019; Edjolo et al., 2016; Graciani et al., 2004; Millán-Calenti et al., 2010; Rodríguez-Sampayo et al., 2011). The Katz-dependency measure includes only BADLs, while the Comprehensive-dependency also IADLs and AADLs and this may be increasing transitions towards dependency with the comprehensive measure. Consequently, operationalizing dependency with a comprehensive measure, including BADLs and IADLs, expands the target population of dependency care policies, even more than when the operationalization uses only BADLs. Moreover, in Uruguay's current NCS the official measure that determines whether a person can be a beneficiary of the program or not, is a comprehensive operationalization of dependency (MIDES, 2018b). Although the methodology of the official scale is not publicly available, it is known that all activities asked in ELPS are included in the official scale construction (MIDES, 2018a, 2018b). Therefore, our results suggested that the comprehensive operationalization of dependency used in the NCS of Uruguay, by expanding the program's target population, may increase program's costs more than when the operationalization of dependency uses only BADLs. While it is desirable to consider a comprehensive measure of

dependency (WHO & WB, 2011), it may be also to consider a more restrictive operationalization to take into account the sustainability of the policy, especially in the long term.

In addition, our results show that increasing age, poorer health and sight impairments are factors associated with a greater number of activities requiring help and higher probability of being dependent at baseline, in keeping with previous studies (Rodríguez-Sampayo et al., 2011; Sousa et al., 2009, 2010). These results are consistent either when we consider the Katz-dependency or the Comprehensive-dependency measures. Besides, hearing difficulties also emerged as a risk factor when we use the Comprehensive-dependency measure, which may be due to the activities included in this measure. In particular, hearing impairments could be affecting Comprehensive-dependency due to "participating in social life" and "communicating" included only in that measure.

Furthermore, in agreement with previous research, the analyses of transitions towards dependency including death show heterogeneity by age, sex, education, health and physical impairments for older people in Uruguay (At et al., 2015; Kingston et al., 2017; Prina et al., 2020; Sousa et al., 2010). Moreover, we showed that results are sensitive to the dependency measure. For instance, moving from non-dependent to dependent state, with the comprehensive measure is associated with sex rather than when the harder operationalization of dependency is used (the Katz-dependency measure). For the latter case, only age and the presence of comorbidity are factors associated with higher risk of transition towards a dependency state.

Consistently with previous literature, our results suggest that women age with poorer health than men (At et al., 2015; Kingston et al., 2017; Prina et al., 2020; Sousa et al., 2010). Older woman with chronic conditions are more likely to enter into dependency state when considering

a comprehensive measure of dependency than men. So, the 'male-female health-survival health paradox' is combined with a higher risk of dependency for older woman indicating that care policies should take this into account to improve their quality of life (Alexandre et al., 2014; Alvarado et al., 2008; Tareque et al., 2017). It is possible that the role of women in the household combined with their poorer health results in women's higher risk of transition into a Comprehensive-dependent state (Millán-Calenti et al., 2010).

Finally, our findings suggest that how dependency is measured is also relevant to understand dependency dynamics over time. Older people with chronic conditions have unmet care needs (Abdi et al., 2019), so it is important to develop care models based around the needs of older people. The differences identified in the risk factors of transiting to a dependent state when using different measures of the construct, provide new insights about how to design and implement policies that provide care to older dependent population living at home. As mentioned above, in the NCS of Uruguay the official scale operationalizes dependency in a comprehensive manner, and our results suggest that in the comprehensive operationalization, women with worse health condition are at greater risk of transitioning to dependency. Therefore, not considering sex to determine whether or not a person is a beneficiary of the program, could generate gender inequities between the older population, to the detriment of women. In addition, this could be worsened if restrictions are applied to program access due to budgetary issues or long-term sustainability of the policy. This could affect the design of interventions to improve quality of life of dependent older people, as our results suggest the need to design sex specific interventions. Further work could deepen knowledge about the type of care required to improve the design of care policies, as our results suggest that the transition to dependency is associated

with different characteristics when using a hard operationalization of the construct rather than when a comprehensive operationalization is used.

A limitation of the current work is that the ELPS study only has two waves. Even though attrition is not a major problem, the analysis of transitions into dependency is limited when data has only two observations maximum per individual. Another drawback is that international comparisons may be hampered by the absence of databases with comparable information in nationally representative samples.

Despite full harmonization of databases is challenging, our analysis extends previous reports from other Latin American countries such as those produced by the 10/66 Dementia Group (Prince, 2009), adding evidence about the population of older adults in Uruguay, and thus allowing a better understanding of dependency in the context of the aging process. Future research on dependency in Uruguay should guarantee the harmonization, that may provide new insights regarding international comparisons, the heterogeneity in the evolution of dependency as individuals age, and the associated need for help.

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Supplementary material

S.1 Analysis of dependency at baseline.

Table S1. Associated factors to dependency at baseline

	(a) Number of activities		(b) Dependent (Y/N)	
	Katz-D	Comprehensive-D	Katz-D	Comprehensive-D
Age	0.004***	0.011***	1.07***	1.07***
	(0.001)	(0.003)	(1.04;1.11)	(1.05;1.10)
≥2 CC	0.080***	0.183***	3.06***	2.76***
	(0.025)	(0.053)	(1.79;5.24)	(1.81;4.19)
Female	-0.509***	-1.109***	0.55	0.97
	(0.129)	(0.279)	(0.03;10.15)	(0.10;9.50)
Female*Age	0.007***	0.016***	1.02	1.01
	(0.002)	(0.004)	(0.98;1.05)	(0.98;1.04)
Female*≥2 CC	-0.028	0.013	0.66	1.14
	(0.031)	(0.066)	(0.35;1.26)	(0.69;1.89)
Primary	0.027*	0.055*	1.61***	1.32**
	(0.015)	(0.032)	(1.16;2.24)	(1.04;1.68)
Sight diff.	0.156***	0.461***	3.13***	3.47***
	(0.028)	(0.060)	(2.22;4.41)	(2.63;4.58)
Hearing diff.	0.090*	0.251**	1.11	1.68**
	(0.050)	(0.108)	(0.57;2.16)	(1.01;2.79)
N	5071	5071	5071	5071

Notes: *** p<0.01, ** p<0.05, * p<0.10 Panel (a): OLS for number of activities requiring help. Katz-D counts help in five activities of Katz-dependency measure and Comprehensive-D in eleven activities of Comprehensive-dependency measure. The values are the estimated coefficients and standard errors in parentheses. Panel (b): logistic regression for dependent state at baseline. Column Katz-D defines dependent if required help in at least one activity of Katz-dependency measure. Comprehensive-D defines dependent if required help in at least one activity of the Comprehensive-dependency measure. The values are the odds ratios and 95% confidence intervals in parentheses.
CC: Chronic conditions.

S.2 Sensitivity analyses for Katz-dependency measure: replacing "Displacing inside home" with the activity of "Changing/maintaining position".

Table S2. Associated factors to dependency at baseline

	(a) Number of activities	(b) Dependent (Y/N)
	Katz-D	Katz-D
Age	0.004***	1.07***
	(0.001)	(1.03;1.10)
≥2 CC	0.083***	3.26***
	(0.023)	(1.87;5.66)
Female	-0.399***	0.35
	(0.122)	(0.02;6.82)
Female*Age	0.006***	1.02
	(0.002)	(0.98;1.06)
Female*≥2 CC	-0.027	0.78
	(0.029)	(0.40;1.53)
Primary	0.022	1.47**
	(0.014)	(1.04;2.07)

Sight diff.	0.152***	3.16***
	(0.026)	(2.21;4.52)
Hearing diff.	0.091*	1.16
	(0.047)	(0.58;2.30)
N	5071	5071

Notes: *** p<0.01, ** p<0.05, * p<0.10 Panel (a): OLS for number of activities requiring help. Katz-D counts help in five activities of Katz-dependency measure and The values are the estimated coefficients and standard errors in parentheses. Panel (b): logistic regression for dependent state at baseline. Column Katz-D defines dependent if required help in at least one activity of Katz-dependency measure. The values are the odds ratios and 95% confidence intervals in parentheses. CC: Chronic conditions.

Table S3. Relative risk ratios for transitions to dependency and death. Base transition ND-ND

	(a) Katz-dependency				
	ND-D	ND-Dth	D-ND	D-D	D-Dth
Age	1.08***	1.08***	1.09**	1.04	1.13***
	(1.05;1.11)	(1.06;1.10)	(1.01;1.19)	(0.99;1.10)	(1.07;1.18)
≥2 CC	2.17***	1.22	4.41*	2.15*	5.17***
	(1.33;3.54)	(0.92;1.62)	(1.09;17.88)	(0.90;5.12)	(2.21;12.08)
Female	1.74	0.05***	26.32	0.02	0.01*
	(0.11;25.69)	(0.01;0.29)	(0.03; 27239.2)	(0.00;2.67)	(0.00;1.75)
Female*Age	0.99	1.03***	0.97	1.05	1.06*
	(0.95;1.02)	(1.01;1.05)	(0.88;1.06)	(0.99;1.12)	(0.99;1.13)
Female*≥2 CC	1.31	1.07	1.10	1.17	0.45
	(0.72;2.41)	(0.72;1.57)	(0.22;5.60)	(0.41;3.44)	(0.16;1.31)

Primary	1.20	1.42***	1.42	1.38*	2.01**
	(0.90;1.59)	(1.16;1.75)	(0.76;2.64)	(0.82;2.31)	(1.08;3.75)
Sight diff.	1.43*	1.42**	3.94***	3.13***	3.64***
	(0.94;2.22)	(1.02;1.96)	(2.06;7.55)	(1.75;5.59)	(2.08;6.37)
Hearing diff.	0.89	1.60*	1.12	1.47	1.32
	(0.45;2.32)	(0.96;2.66)	(0.26;4.95)	(0.50;4.35)	(0.48;3.60)
N	5071	5071	5071	5071	5071

Notes: 95% confidence intervals in parentheses; *** p<0.01, ** p<0.05, * p<0.1

ND-ND: Non-dependent to Non-dependent; ND-D: Non-dependent to Dependent; ND-Dth: Non-dependent to Death; D-ND: Dependent to Non-dependent; D-D; Dependent to Dependent; D-Dth: Dependent to Death.

CC: Chronic conditions.

S.3 Sensitivity analyses using the subsample of individuals responding the survey themselves

Table S4. Associated factors to dependency at baseline

	(a) Number of activities		(b) Dependent (Y/N)	
	Katz-D	Comprehensive-D	Katz-D	Comprehensive-D
Age	0.002*	0.006**	1.063***	1.065***
	(0.001)	(0.002)	(1.02;1.11)	(1.03;1.10)
≥2 CC	0.064***	0.132***	4.051***	2.810***
	(0.017)	(0.038)	(2.08;7.89)	(1.70;4.65)
Female	-0.172*	-0.449**	1.380	2.131
	(0.093)	(0.203)	(0.04;47.38)	(0.14;31.63)
Female*Age	0.002*	0.006**	1.002	0.994

	(0.001)	(0.003)	(0.96;1.05)	(0.96;1.02)
Female*≥2 CC	-0.017	0.042	0.710	1.471
	(0.021)	(0.047)	(0.32;1.59)	(0.80;2.71)
Primary	0.020*	0.030*	1.636**	1.180**
	(0.010)	(0.022)	(1.11;2.42)	(0.90;1.54)
Sight diff.	0.117***	0.377***	3.168***	3.761***
	(0.021)	(0.046)	(2.07;4.86)	(2.72;5.19)
Hearing diff.	0.030*	0.198**	1.686	1.886**
	(0.042)	(0.093)	(0.72;3.95)	(0.98;3.64)
N	4868	4868	4868	4868

Notes: *** p<0.01, ** p<0.05, * p<0.10 Panel (a): OLS for number of activities requiring help. Katz-D counts help in five activities of Katz-dependency measure and Comprehensive-D in eleven activities of Comprehensive-dependency measure. The values are the estimated coefficients and standard errors in parentheses. Panel (b): logistic regression for dependent state at baseline. Column Katz-D defines dependent if required help in at least one activity of Katz-dependency measure. Comprehensive-D defines dependent if required help in at least one activity of the Comprehensive-dependency measure. The values are the odds ratios and 95% confidence intervals in parentheses.

CC: Chronic conditions.

Table S5. Relative risk ratios for transitions to dependency and death. Base transition ND-ND

	(a) Katz-dependency					(b) Comprehensive-dependency				
	ND-D	ND-Dth	D-ND	D-D	D-Dth	ND-D	ND-Dth	D-ND	D-D	D-Dth
Age	1.09***	1.08***	1.11***	1.04	1.12***	1.10***	1.08***	1.05	1.08***	1.13***
	(1.06;	(1.06;	(1.03;	(0.91;	(1.04;	(1.07;	(1.07;	(0.99;	(1.03;	(1.07;
	1.13)	1.10)	1.20)	1.11)	1.19)	1.13)	1.10)	1.11)	1.14)	1.20)
≥2 CC	1.89**	1.22	3.37*	2.90**	8.91***	1.29	1.15	1.79	2.71**	5.06***
	(1.11;	(0.92;	(0.94;	(1.04;	(2.47;	(0.87;	(0.86;	(0.69;	(1.23;	(2.03;
	3.20)	1.61)	12.11)	8.12)	32.10)	1.92)	1.56)	4.60)	5.95)	12.58)
Female	8.33	0.05***	531.52*	0.01	0.17	4.16	0.05***	3.37	1.83	0.47**
	(0.46;	(0.01;	(0.59;	(0.00;	(0.00;	(0.51;	(0.01;	(0.02;	(0.03;	(0.00;
	150.99)	0.31)	479000)	3.50)	125.31)	33.99)	0.35)	560.0)	125.89)	9.69)
Female*Age	0.97	1.03**	0.93*	1.06	1.03	0.98	1.03**	0.98	1.00	1.04**
	(0.94;	(1.01;	(0.85;	(0.98;	(0.95;	(0.96;	(1.00;	(0.91;	(0.94;	(0.98;
	1.01)	1.05)	1.01)	1.15)	1.12)	1.01)	1.06)	1.05)	1.05)	1.12)
Female*≥2 CC	1.47	1.09	1.22	1.35	0.22**	1.93**	1.16	3.70**	1.88	0.77

	(0.78;	(0.74;	(0.27;	(0.36;	(0.05;	(1.22;	(0.76;	(1.13;	(0.74;	(0.25;
	2.77)	1.60)	25.45)	5.07)	0.98)	3.06)	1.76)	12.09)	4.77)	2.34)
Primary	1.10	1.43***	1.44	1.81*	2.02**	1.27***	1.37***	1.10	1.16	1.85***
	(0.82;	(1.16;	(0.79;	(0.93;	(0.95;	(1.03;	(1.10;	(0.69;	(0.80;	(1.05;
	1.47)	1.76)	2.65)	3.55)	4.29)	1.57)	1.71)	1.75)	1.70)	3.25)
Sight diff.	1.29	1.35*	3.91***	1.95***	4.41***	1.82***	1.32	5.23***	3.79***	4.87***
	(0.79;	(0.97;	(2.01;	(0.84;	(2.20;	(1.28;	(0.88;	(3.00;	(2.35;	(2.77;
	2.11)	1.88)	7.60)	4.51)	8.84)	2.60)	2.00)	9.12)	6.13)	8.55)
Hearing diff	0.46	1.57*	1.57	1.78	1.93	0.77	1.38	2.27	1.29	2.35**
	(0.11;	(0.94;	(0.35;	(0.40;	(0.53;	(0.33;	(0.67;	(0.74;	(0.43;	(0.87;
	1.96)	2.63)	7.01)	7.94)	6.97)	1.80)	2.83)	6.28)	3.87)	6.33)
N	4868	4868	4868	4868	4868	4868	4868	4868	4868	4868

Notes: 95% confidence intervals in parentheses; *** p<0.01, ** p<0.05, * p<0.1

ND-ND: Non- dependent to Non-dependent; ND-D: Non-dependent to Dependent; ND-Dth: Non-dependent to Death;

D-ND: Dependent to Non-dependent; D-D; Dependent to Dependent; D-Dth: Dependent to Death. CC: Chronic conditions.

S.4 Additional analyses.

Table S6. Relative risk ratios for various specifications of the multinomial model

	Transition ND-D for Katz-Dependency								
Age	1.08***	1.08***	1.07***	1.07***	1.07***	1.08***	1.08***	1.07***	1.08***
	(1.06;	(1.06;	(1.06;	(1.06;	(1.05;	(1.05;	(1.05;	(1.06;	(1.05;
	1.09)	1.09)	1.09)	1.09)	1.09)	1.12)	1.12)	1.09)	1.12)
≥ 2 CC		2.78***	2.79***	2.75***	2.62***	2.61***	2.16***	2.61***	2.16***
		(2.12;	(2.12;	(2.09;	(1.98;	(1.97;	(1.31;	(1.97;	(1.31;
		3.66)	3.67)	3.61)	3.46)	3.45)	3.57)	3.45)	3.56)
Primary			1.21	1.20	1.20	1.20	1.20	1.20	1.20
			(0.92;	(0.90;	(0.91;	(0.91;	(0.90;	(0.91;	(0.90;
			1.61)	1.59)	1.60)	1.60)	1.59)	1.60)	1.59)
Sight diff.				1.44	1.43	1.43	1.43	1.44*	1.44*
				(0.93;	(0.92;	(0.92;	(0.92;	(0.93;	(0.93;
				2.22)	2.20)	2.21)	2.20)	2.23)	2.23)
Hearing diff				0.87	0.88	0.89	0.89	0.85	0.87
				(0.37;	(0.37;	(0.37;	(0.37;	(0.35;	(0.36;
				2.09)	2.10)	2.13)	2.14)	2.05)	2.08)
Female					1.32*	3.13	2.87	1.37**	2.75
					(0.98;	(0.20;	(0.18;	(1.01;	(0.18;
					1.78)	48.59)	45.03)	1.86)	43.00)
Female*Age						0.99	0.99		0.99

						(0.95; 1.02)	(0.95; 1.02)		(0.95; 1.03)
Female*≥2 CC							1.31 (0.72; 2.41)		1.31 (0.71; 2.40)
Lives alone								0.80 (0.61; 1.05)	0.80 (0.61; 1.05)
BIC	-36093	-36148	-36121	-36069	-36081	-36045	-35999	-36044	-35962
N	5071	5071	5071	5071	5071	5071	5071	5071	5071

Notes: 95% confidence intervals in parentheses; *** p<0.01, ** p<0.05, * p<0.1

ND-D: Non-dependent to Dependent. The minimum BIC reflects the best model regarding to fit adjust.

Table S7. Relative risk ratios for various specifications of the multinomial model

	Transition ND-D for Comprehensive-Dependency								
Age	1.09***	1.09***	1.09***	1.08***	1.08***	1.09***	1.09***	1.08***	1.09***
	(1.08;	(1.08;	(1.07;	(1.07;	(1.07;	(1.07;	(1.07;	(1.07;	(1.07;
	1.10)	1.10)	1.10)	1.10)	1.10)	1.12)	1.12)	1.10)	1.12)
≥ 2 CC		2.23***	2.24***	2.18***	2.00***	1.99***	1.30	1.99***	1.30
		(1.84;	(1.86;	(1.80;	(1.65;	(1.64;	(0.89;	(1.64;	(0.89;
		2.69)	2.71)	2.64)	2.43)	2.42)	1.91)	2.42)	1.91)
Primary			1.34***	1.33***	1.34***	1.34***	1.33***	1.34***	1.33***
			(1.10;	(1.08;	(1.10;	(1.10;	(1.08;	(1.10;	(1.08;
			1.65)	1.63)	1.65)	1.65)	1.63)	1.65)	1.63)
Sight diff.				1.87***	1.85***	1.85***	1.86***	1.87***	1.88***
				(1,35;	(1.33;	(1.33;	(1.34;	(1.35;	(1.35;
				2.59)	2.57)	2.57)	2.58)	2.60)	2.61)
Hearing diff				1.45	1.49	1.50	1.52	1.47	1.51
				(0.80;	(0.82;	(0.82;	(0.83;	(0.81;	(0.82;
				2.64)	2.71)	2.74)	2.78)	2.69)	2.76)
Female					1.69***	3.95	3.12	1.75***	2.95
					(1.37;	(0.53;	(0.41;	(1.41;	(0.39;
					2.10)	29.70)	23.54)	2.17)	22.31)
Female*Age						0.99	0.99		0.99
						(0.96;	(0.96;		(0.96;

						1.02)	1.02)		1.02)
Female*≥2 CC							1.79**		1.79**
							(1.15;		(1.15;
							2.80)		2.80)
Lives alone								0.84*	0.84*
								(0.69;	(0.69;
								1.02)	1.02)
BIC	-33872	-34025	-34002	-34000	-34046	-34006	-33965	-34016	-33935
N	5071	5071	5071	5071	5071	5071	5071	5071	5071

Notes: 95% confidence intervals in parentheses; *** p<0.01, ** p<0.05, * p<0.1

ND-D: Non-dependent to Dependent. The minimum BIC reflects the best model regarding to fit adjust.

Table S8. Relative risk ratios for multinomial model. Subsample with information on income

Transition ND-D for						
	Katz-dependency			Comprehensive-dependency		
Age	1.07***	1.07***	1.07***	1.09***	1.09***	1.10***
	(1.03;	(1.03;	(1.03;	(1.07;	(1.07;	(1.07;
	1.10)	1.10)	1.11)	1.21)	1.12)	1.12)
≥ 2 CC	2.56***	2.55***	2.58***	1.31	1.30	1.32
	(1.47;	(1.46;	(1.48;	(0.87;	(0.86;	(0.87;
	4.46)	4.44)	4.51)	1.98)	1.98)	1.99)
Primary	1.30	1.30	1.15	1.28**	1.28**	1.19
	(0.94;	(0.93;	(0.81;	(1.01;	(1.01;	(0.93;
	1.81)	1.80)	1.64)	1.61)	1.61)	1.53)
Sight diff.	1.38	1.40	1.38	1.76***	1.77***	1.75***
	(0.85;	(0.86;	(0.84;	(1.22;	(1.23;	(1.22;
	2.26)	2.28)	2.26)	2.52)	2.53)	2.52)
Hearing diff	0.93	0.90	0.92	1.51	1.50	1.52
	(0.36;	(0.35;	(0.35;	(0.79;	(0.78;	(0.79;
	2.41)	2.25)	2.40)	2.89)	2.88)	2.92)
Female	0.93	0.89	0.75	3.22	3.07	2.82
	(0.43;	(0.41;	(0.03;	(0.35;	(0.33;	(0.30;
	20.20)	19.28)	16.57)	29.90)	28.49)	26.29)
Female*Age	1.00	1.00	1.01	0.99	0.99	0.989

	(0.96;	(0.96;	(0.97;	(0.96;	(0.96;	(0.96;
	1.04)	1.05)	1.05)	1.02)	1.02)	1.02)
Female*≥2 CC	1.21	1.21	1.20	1.90**	1.90**	1.89**
	(0.61;	(0.61;	(0.61;	(1.16;	(1.16;	(1.16;
	2.40)	2.40)	2.38)	3.10)	3.10)	3.09)
Lives alone		0.80	0.71**		0.87	0.82*
		(0.59;	(0.51;		(0.70;	(0.64;
		1.09)	0.99)		1.08)	1.02)
Income (log)			0.80*			0.89
			(0.63;			(0.75;
			1.01)			1.05)
BIC	-28611	-28579	-28545	-26872	-26846	-26814
N	4162	4162	4162	4162	4162	4162

Notes: 95% confidence intervals in parentheses; *** p<0.01, ** p<0.05, * p<0.1
ND-D: Non-dependent to Dependent. The minimum BIC reflects the best model regarding to fit adjust.

Chapter 3: Operationalization of care dependency in the community-dwelling older adults: a systematic review

Abstract

Background and Objectives

Population aging may increase the demand for care and poses the challenge of operationalizing care dependency. There is no consensus on how to operationalize care dependency. Hence, we aimed to analyze the operationalization of care dependency for community-dwelling older adults to critically discuss the instruments, questions and/or variables used in the literature.

Research Design and Methods

We systematically reviewed publications since 2001 and included observational studies analyzing care dependency in the community-dwelling population of older adults aged 60 or 65 years and older. The protocol of this review was pre-registered at PROSPERO 2021 CRD42021241083.

Results

The searches resulted in 2699 publications of which 69 met our criteria. There was a large degree of heterogeneity in the operationalization of care dependency. However, most studies (84%) operationalize the construct by including questions and/or answers from individuals in which the need for help from another person to perform Activities of Daily Living was explicitly mentioned. Some publications used validated instruments (19%), but most modified these instruments or developed their own to assess care dependency. Care dependence research conducted in low- and middle-income countries was overrepresented.

Discussion and Implications

It is good practice to explicitly mention in the questions and/or answers the need for help from another person when operationalizing care dependence. In turn, studies on aging would benefit from reporting adequate information, considered in the current context, to assess care dependency in aging research to improve its understanding.

Keywords: Care Dependency; Activities of Daily Living; Operationalization; Older Adults; Systematic Review

JEL code: I10, I31, J14

Background

Population aging has been studied by scholars in different disciplines including economics, epidemiology, social sciences and other health sciences in most developed countries (Kingston et al., 2017, 2018; Melzer et al., 2000; Navarro Espigares et al., 2008; WHO, 2015) as is a process that has multiple consequences that concerns each of these disciplines. In recent decades, population aging has also become a topic of concern in developing countries, as the increase in life expectancy and the higher proportion of older adults who live longer has become a global issue (Bloom et al., 2010; Prina et al., 2020; Sousa et al., 2010). Although, demographic transition is perceived as a good symptom for pursuing development, it can also be challenging as it transforms the age structure of the population which is related to health and social care needs (Galiani et al., 2017; United Nations, 2020). For instance, social security, health, and social care systems may suffer from sustainability problems, as older age is associated with poor health outcomes, such as comorbidity, disability, and care dependency (Navarro Espigares et al., 2008; Villalobos Dintrans, 2020). In addition, population aging may increase the potential demand for health and social care services, and this demand may not be adequately met, harming the well-being of people with these needs (Abdi et al., 2019). Furthermore, global aging poses the challenge of conceptualizing and operationalizing care dependency for older adults to achieve comparability and harmonization across countries, studies, and settings, the recent aging process experienced in low- and middle-income countries have transformed this into a global issue (WHO, 2015).

Dependency is a multidimensional construct that could refer to functional, psychosocial and supportive dimensions and that could also include an economic dimension (Rely et al., 2020; WHO, 2015). We are interested in the construct of dependency related to care, the *care*

dependency, defined as the need for human help or care beyond that habitually required (Harwood et al., 2004). Thus, care dependency arises when functional capacity has declined to a point where a person is no longer able to perform the tasks of daily living without the help of others and reflects the decline that cannot be compensated for by the older person's environment or by the use of assistive devices. (WHO, 2015). Care dependency is related to disability, which is defined as an umbrella term for impairments, activity limitations, and participation restrictions, however these constructs are different, as care dependency takes into account the need for help from another person, whereas disability does not (WHO, 2001).

There is no consensus on how operationalize care dependency. In previous work, care dependency has been operationalized using instruments based on the needs for help to perform Activities of Daily Living (ADLs), including basic, instrumental, and/or advanced activities (WHO, 2001, 2015). However, there are other instruments for care dependency, such as the Isaacs and Neville's (1976) instrument based on the time interval needing help (Isaacs and Neville, 1976). Even when these are used, there are inconsistencies according to the selected instrument, the number and type of ADLs included, the type of responses to the questions (yes/no or scaled responses). Therefore, it is important to understand the different operationalizations to provide accurate estimates and recommendations for policies targeting older people with care dependency, especially when making comparisons across studies, settings, or regions (WHO, 2015).

This systematic review looks at the operationalization of the care dependency construct for the community-dwelling older adults. It critically discusses the instruments, questions and/or variables used in previous literature since the World Health Organization (WHO) published the International Classification of Functioning (ICF) two decades ago (WHO, 2001). We aim to

answer: How is the construct of dependency (need for help, care or support) operationalized for the older population living in the community? The older adults have different patterns of aging, resulting in heterogeneity of health conditions, disability and care dependency (Amengual et al., 2021; Dorantes-Mendoza et al., 2007; Luo and Li, 2020; Marroig et al., 2022; Rely et al., 2020), and different operationalizations of care dependency can inform about different aspects experienced by older adults (Millán-Calenti et al., 2010). The results of this systematic review contribute to the understanding of aging and the operationalization of care dependency with a global perspective. In fact, they may be useful for future research that analyzes: how to target long-term care policies, how to ensure an adequate quality of life for community-dwelling older adults and their families, how to achieve sustainability of these policies, and how to perform international comparison and harmonization.

Methods

This systematic review followed standard guidelines from the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009). A protocol was published on the International Prospective Register of Systematic Review (PROSPERO), reference; PROSPERO 2021 CRD42021241083 (https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42021241083).

Literature search

A preliminary search was conducted by identifying relevant articles and related terminology to care dependency. The terms covered Dependency, Functional dependency, Activities of daily living, Needs Assessment, Long-Term Care, Operationalization, Older Adults, and Aged. The bibliographic advisors identified the appropriate terminology and designed a specific search strategy for each database, from 2001 to 2022: PUBMED (via MEDLINE); SCOPUS (Via

Timbo, academic provider of the University of the Republic); (EBSCO, access through the University of the Republic, includes EconLit with Full Text, Health Source: Nursing/Academic Edition; Library, MedicLatina, Professional Development Collection, Regional Business News, PSICODOC), LILACS and IBECS databases via BVS (PAHO/WHO), and Epistemonikos. Additional search strategy information can be found in the Supplementary material (see Systematic review search).

Eligibility criteria

Inclusion: original peer-reviewed research published in English, Spanish or Portuguese from observational studies analyzing samples of people aged 60 or 65 years or older living in the community. The period of search was from 2001 to 2022 and the publications were community-based study designs, including, prospective and retrospective cohort studies, and cross sectional studies. Eligible studies report the instruments, questions and/or variables used to operationalize care dependency.

Exclusion: narrative reviews, letters, editorials, systematic reviews, meta-analyses, viewpoints, comments, books and chapters, conference abstracts, dissertations. Also studies of hospitalized and institutionalized older patients, and studies that examined a specific population (i.e., all participants had Alzheimer's disease or have specific values of the Mini Mental State Examination, MMSE).

Selection of publications

Citations retrieved from searches were appraised independently by two researchers (AM and MC/JC/GMT) at the title and abstract level. Then, two researchers (AM and MC/JC/GMT) independently evaluated the full texts of those identified as being potentially eligible, or over which there is doubt regarding eligibility.

Data extraction

AM extracted data and assessed the quality of the included publications. A second researcher evaluated 50% of the extracted data and quality assessment (MC, JC or GMT). At each stage, discrepancies between judgments were resolved by a third author (MC, JC or GMT). We used the *"STrengthening the Reporting of OBservational studies in Epidemiology"* statement (STROBE) to assess the quality of observational studies, based on 21 items (Vandenbroucke et al., 2007). Also, the modified Leboeuf-Yde and Lauritsen tool, covering internal and external validity aspects, was used to assess the risk of bias of the included prevalence studies (Hoy et al., 2012).

Data analysis

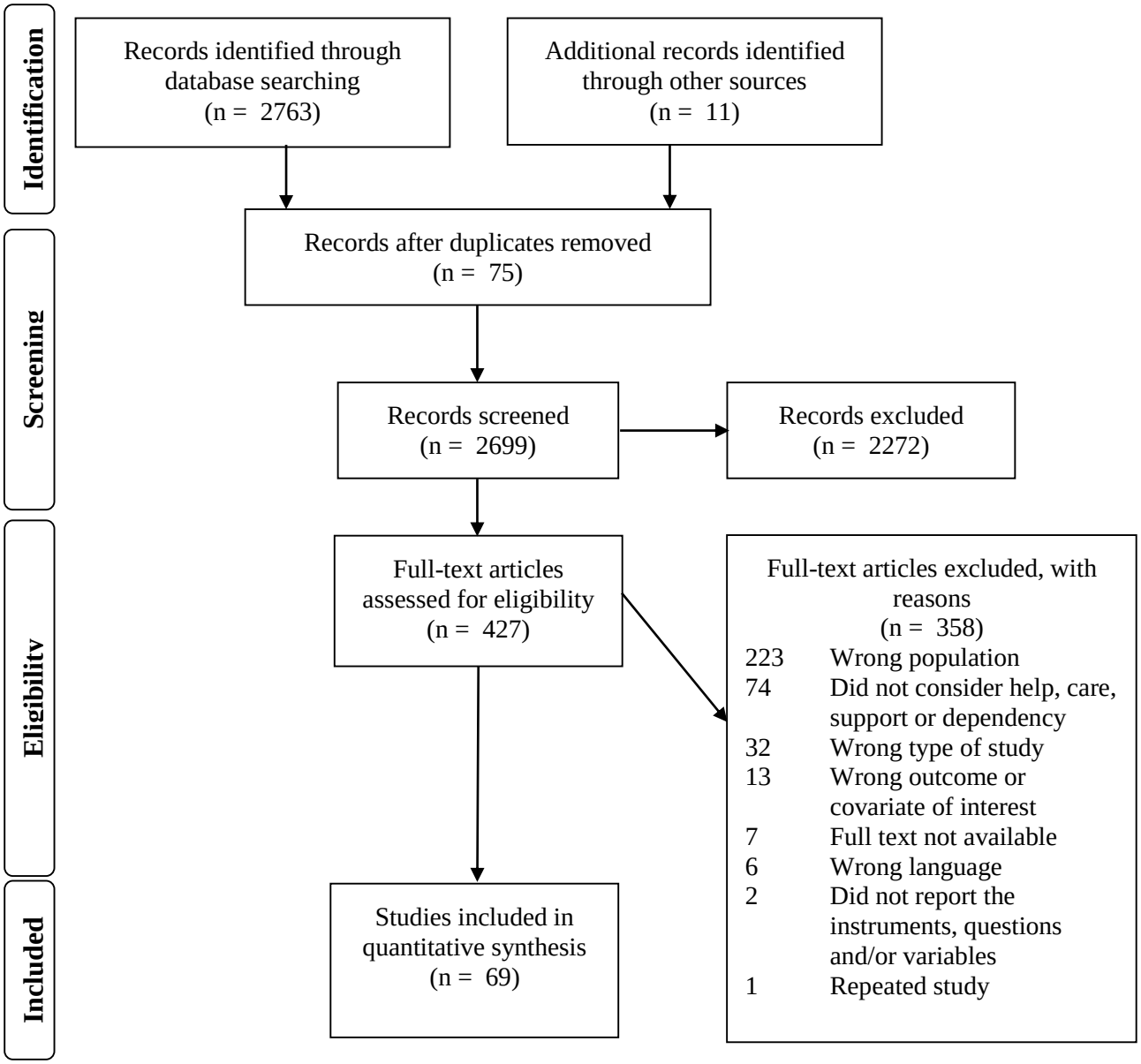
The citations retrieved from bibliographic databases and manual searches were imported into the bibliographic management *Zotero* and then to *Covidence*. In *Covidence*, we screened the titles and abstracts and assessed the full texts of the publications. Finally, we extracted the data and assessed the quality of the included publications. We present a narrative critical analysis of the instruments and variables used to operationalize dependency and the quantitative synthesis of the prevalence of dependency for a subsample of publications.

Results

A total 2774 publications were identified through systematically searches of the bibliographic databases, and 11 records through hand searching. After eliminating duplicate records, the titles and abstracts of 2699 publications were read and screened. Subsequently, the full texts of 427 publications were screened and 69 of these publications met the eligibility criteria and were included in our analysis.

Figure 1 shows the PRISMA flow diagram illustrating the process explained above and detailing the reasons for exclusion. Most of the publications were excluded because the population analyzed did not met the eligibility criteria ("Wrong Population", n=223). That is, publications concerned with populations that have some particular characteristic, for instance, participants who had been diagnosed with a disease or had some syndrome (e.g., Alzheimer's disease or were frail), participants were hospitalized, institutionalized or recently discharged patients, participants were beneficiaries of a care program, participants were excluded using a specific exclusion criteria (e.g., participants were women or had a cognitive level above/below a certain threshold of a cognitive instrument). Another reason for exclusion was that the operationalization did not consider the need for help, care or support nor explicitly mention dependency of the older adults ("Did not consider help, care, support or dependency", n=74). However, it is worth mentioning that we included publications that explicitly use the term "dependency/e" even though they do not consider help, care or support required by older adults. In these cases, we aimed to evaluate the instruments or variables used as a "proxy" or whether dependency was inaccurately operationalized.

Figure 1. PRISMA diagram showing the pathway of systematically reviewing the operationalization of care dependency in the community-dwelling older adults



Likewise, publications were excluded if they were focused on caregivers or were controlled trials ("Wrong type of study", n=32). In addition, we excluded publications that used questions or variables related to the need for help as part of other construct, for instance a frailty indicator ("Wrong outcome variable or covariate of interest", n=13). Finally, other reasons for exclusion were the inability to access the full text even after contacting the authors ("Full text not available", n=7), the language was other than English, Spanish or Portuguese ("Wrong language", n=6), the instruments, questions and/or variables were not stated ("Did not report the instruments, questions and/or variables", n=2), and the paper was repeated ("Repeated study", n=1) (See Figure 1).

Characteristics of included publications

Table 1 presents the main characteristics of the included publications. Among them, the data was collected in Latin American countries (n=40), in Europe (n=20), in other regions (n=6), and in multiple regions (n=3). Amongst the publications from Latin America 58% were from Brazil and 20% from Mexico. In Europe, 55% of the publications were from Spain.

Other publications used data from Colombia (n=3), France (n=3), Chile (n=2), China (n=2), Cuba (n=2), Italy (n=2), Australia (n=1), Burkina Faso (n=1), Dominican Republic (n=1), England (n=1), India (n=1), the Netherlands (n=1), Peru (n=1), Portugal (n=1), Switzerland (n=1), and Taiwan (n=1). Finally, three publications performed multiple country analyses utilizing the population-based studies of aging and dementia in low- and middle-income countries from the 10/66 Dementia Research Group (At et al., 2015; Prina et al., 2020; Sousa et al., 2010).

In most of the studies conducted in Latin American countries, the population analyzed was of individuals aged 60 years or older, while in most of the studies conducted in European countries

or other regions, such as in Australia, China, or Taiwan, the population is of individuals aged 65 years or older.

Table 1. Characteristics of included publications (Nº=69)

	Nº	Author/s (Year)	Analyzed population ≥ 60	Analyzed population ≥ 65	Baseline N	Type *Need for Help*[5]	Sev.[6]
Latin America	**40**						
Brazil	23	Boggio et al, 2015		X	401	A&L	Yes
		Brito et al, 2018	X		2403[1]	A&L	Yes
		Campos Cavalcanti et al, 2008	X		310	QA&L	
		Cardoso & Costa, 2010	X		254	QA&L	Yes
		Castro & Guerra, 2008	X		213	L	
		Floriano & Dalgalarrondo, 2007	X		82	L	
		Fogal et al, 2019	X		499	A	Yes
		Francisco et al, 2021		X	741	A&L	
		Gavasso & Beltrame, 2017	X		272	L	
		Giacomin et al, 2008	X		1786	L	Yes
		Gontijo et al, 2016	X		1995	A	Yes
		Kessler et al, 2018	X		1593	QA&L	
		Lima et al, 2019	X		196	QA&L	
		Lima-Costa et al, 2016	X		23815	QA&L	
		Lini et al, 2016	X		196	L	
		Maciel & Guerra, 2006	X		310	L	Yes
		Moraes et al, 2015	X		1133	A&L	
		Nunes et al, 2017	X		1593	A&L	
		Queiroz et al, 2014	X		316	A&L	Yes
		Rigo et al, 2010	X		34	A&L	Yes
		Santos et al, 2014	X		316	A&L	Yes
		Silva et al, 2016	X		441	QA&L	
		Silva et al, 2019		X	109	QA&L	
Mexico	8	Ávila Funes et al, 2006	X		1748	QA&L	
		Barragán-Berlanga et al, 2007		X	4417	L	
		Barrantes-Monge et al, 2007		X	4862	A&L	Yes
		Cervantes Becerra et al, 2015	X		300	QA&L	Yes
		Díaz de León González et al, 2012	X		4774	QA&L	
		Dorantes-Mendoza et al, 2007	X		7171	QA&L	
		Mendoza-Meléndez et al, 2015		X	2098	QA&L	
		Rely et al, 2020	X		3784[2]	L	
Colombia	3	Cano Gutiérrez et al, 2018	X		2000	QA&L	
		Cortés-Muñoz et al, 2016	X		4248	QA&L	
		Germán Borda et al, 2016	X		2000	QA&L	
Chile	2	Lobos et al, 2016	X		389	A&L	
		Muñoz Peñailillo et al, 2004		X	575	QA&L	
Cuba	2	García Otero et al, 2010	X		180	QA&L	
		Millán Méndez, 2010	X		195	QA&L	
Peru	1	Varela-Pinedo et al, 2015	X		501	QA&L	
Dominican Republic	1	Oliver et al, 2009		X	1397	QA&L	
Europe	**20**						
Spain	11	Alcañiz et al, 2015		X	913	QA&L	
		Blanco-Reina et al, 2021		X	582	QA&L	
		Brugulat-Guiteras et al, 2011		X	3566	QA&L	
		Fernández-Olano et al, 2006		X	787	L	Yes
		García Pérez et al, 2010		X	125	QA&L	
		Gutiérrez-Valencia et al, 2019		X	7023	QA&L	Yes
		Lázaro Alquézar et al, 2007		X	380	QA&L	Yes

		Moral-García et al, 2020	X		515	Q&A	
		Navarro Espigares et al, 2008		X	11431[(1)]	QA&L	Yes
		Otero et al, 2003		X	1135	QA&L	Yes
		Torres Buisan, 2004		X	434	QA&L	
France	3	Edjolo et al, 2016		X	3238	A&L	
		Paraponaris et al, 2012	X		8745	Q&A	
		Roquebert et al, 2018	X		2226	QA&L	
Italy	2	De Ronchi et al, 2005		X	216	L	
		Montanari et al, 2011		X	3150	A	
England	1	Kingston et al, 2018		X	41323[(1)]	QA&L	Yes
Portugal	1	Rodrigues et al, 2014		X	1684[(2)]	A	
Switzerland	1	Rudnytskyi & Wagner, 2019		X	4026	L	Yes
The Netherlands	1	Gobbens, 2019		X	355	A&L	
Other regions	**6**						
Australia	1	Howe, 2008		X	2644374[(3)]	QA&L	
Burkina Faso	1	Berthé et al, 2014	X		351	A&L	Yes
Taiwan	1	Chen et al, 2011		X	810	A	
China	2	Cao et al, 2021		X	16151	A	
		Chou & Leung, 2008	X		8995[(1)]	Q&A	
India	1	Peter et al, 2022	X		7200	QA&L	
Multiple countries	**3**						
10/66 DRG[(4)]	3	At et al, 2015		X	11251[(1)]	QA&L	Yes
		Prina et al, 2020		X	16990[(1)]	QA&L	
		Sousa et al, 2010		X	15022[(1)]	QA&L	

Notes: [(1)] Sum of various countries and/or various years of cross-sectional samples. [(2)] The subpopulation in the age range of interest (i.e. 60 or 65 years and over) of the total population considered in the study. [(3)] Census of the population in the age range of interest. [(4)] 10/66 Dementia Research Group's: population-based studies of aging and dementia in low and middle income countries. [(5)] Identification of the type in which need for help is stated in the publications: QA&L: in questions, answers, and in the labels of the variable of interest (n=36); A&L: in answers and the labels of the variable (n=13); L: in the labels of the variable (n=11); A: in the answers (n=6); Q&A: in the questions and answers (n=3). [(6)] Severity: identify the publications in which severity of dependency was stated.

The operationalization of care dependency

The need for help, care or support was evaluated in three different ways in the operationalization of care dependency. First, participants were asked directly questions, such as, “because of a health problem, the individual needs the help or company of others to perform the usual activities of daily living”. Second, the need for help was derived from participants’ responses to any question, including the wording such as “required help to perform the activities of daily living”. Finally, a third source for identifying care dependency was using a variable of interest that was labeled with a dependency term, such as “ADL dependent” or “Low/High dependency”.

We classified the included publications according to the different types of identification of the need for help (See Table 1). Most of the publications operationalize care dependency by identifying the need for help in these three sources simultaneously, that is, in the questions, answers, and in the labels of the variable of interest (labelled as *QA&L*, n=36). Some publications identify the need for help with the participants' answers and the labels of the variable measuring dependence (labelled as *A&L*, n=13), without wording the need for help in the questions. Similarly, other publications consider dependency only in the labels of the variable (labelled as *L*, n=11), but do not explicitly mention the need for help in the questions nor in the participants’ answers. We also identified publications in which the need for help is only stated in the participants' answers to the questions (labelled as *A*, n=6). Finally, some studies stated the need for help explicitly in the questions and answers of the individuals but do not translate it into corresponding labels for the variable measuring dependence (labelled as *Q&A*, n=3).

Several publications (n=21) assess the severity of care dependency (See Table 1). Indeed, the severity of dependency was assessed either by establishing cut-off points to the index or by counting the number of activities with dependency (n=15), by establishing a hierarchy according to the type of activity with dependency (n=4), or by establishing time intervals in which help is needed (n=2), such as defining help required daily, weekly or monthly.

Instruments, scales and ADLs considered

Table 2 presents the distribution of publications according to the instrument used to operationalize care dependency. In almost half of the publications, the authors did not use recognized instruments (n=30). In fact, specific questions were developed and the requirement for help is asked in the questions and/or incorporated in the answers given by the participants. The other half of the publications used recognized instruments to operationalize dependency in their original form (n=13) or introducing some modifications (n=26). The most commonly used instruments were the Barthel index (Mahoney and Barthel, 1965), the Katz index (Katz et al., 1963), the Lawton and Brody index (Lawton and Brody, 1969), and combinations of them.

Furthermore, 65 publications used ADLs to operationalize care dependency and only four used open-ended questions by interviewers to assess the time of care needed and operationalize dependency (At et al., 2015; Moral-García et al., 2020; Prina et al., 2020; Sousa et al., 2010).

The publications considered different types of activities namely basic, instrumental, and/or advanced activities or a combination of them. Most of the publications included basic and instrumental ADLs jointly (n=19) and separately (n=18), other publications considered only basic activities (n=17), and four included instrumental activities. The rest of the publications included basic, instrumental, and advanced activities separately (n=1), instrumental and advanced activities separately (n=1), self-care, mobility, housework and communication

activities (n=2), and three publications did not report the specific activities considered (See Table S1 in Supplementary material).

Table 2. Distribution of publications by the instrument used to operationalize care dependency

Instrument	Original	Modified	None
Barthel Index	4	1	
Barthel Index and Lawton & Brody Index	1	1	
Katz Index	3	8	
Katz Index and Lawton & Brody Index	1	11	
Katz Index, Lawton & Brody and EVA Scale*	1		
Lawton & Brody Index	2	1	
Groningen Activity Restriction Scale (GARS)	1		
Interval of need Isaacs & Neville		1	
Older American Resources (OARS)-MFAQ		2	
Functional Autonomy Measurement System (SMAF)		1	
No recognized instrument			30
Total	**13**	**26**	**30**

Specifically, the activities that were considered are mostly those included in the Barthel, Katz and Lawton and Brody indexes. Basic activities were the most used, including “Eating”, “Dressing”, “Bathing”, “Going to the toilet”, or “Transferring” (i.e., moving in/out of bed or chair). There was inconsistency in the wording of “Transfer” activity which was also referred as “Physical ambulation”. “Continence”, was less used and “Grooming” was included in few studies. As for instrumental activities, the most frequently used were “Shopping”, “Ability to handle finances”, and “Food preparation”, followed by “Transportation” (i.e. outside the home), “Responsibility for own medication”, and “Housekeeping”. Lastly, “Ability to use the telephone” and “Laundry” were included in few studies. Only one paper used advanced activities (i.e., “Communication”).

Finally, there was heterogeneity in the criteria to determine if a person is care dependent or not. For this purpose, the publications considering unmodified instruments used their default scale

(i.e., Barthel, Katz or Lawton). However, most of the publications used "yes/no" answers to the question of whether they needed help to perform ADLs, and an individual was considered care dependent if he/she needs help to perform at least one ADL. Finally, other publications rank dependence using the type of the activity (i.e., individuals are non-dependent, or dependent in instrumental activities, or dependent in basic and/or instrumental ADLs.).

Quality of included publications

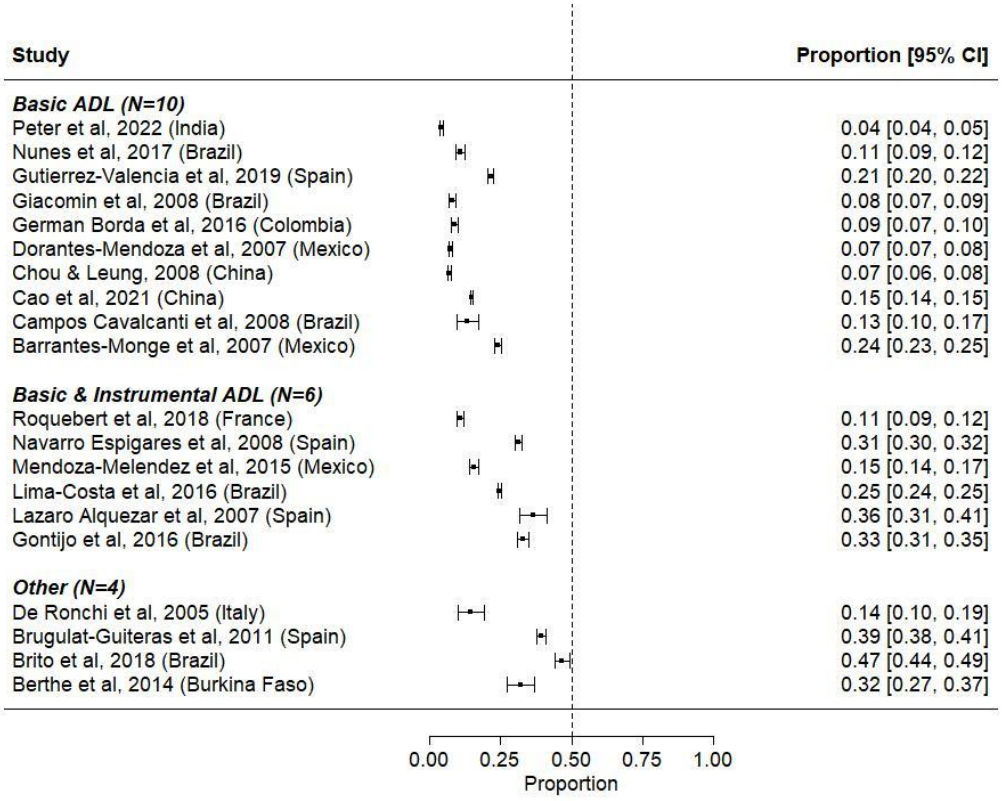
There were four publications that did not explain the background and rationale of the investigation (García Otero et al., 2010; García Pérez et al., 2010; Millán Méndez, 2010; Varela-Pinedo et al., 2015) and only one publication did not state the objectives (Rodrigues et al., 2014). In the "Methods" section the items that are missing in most publications refer to how to analyze biases (item 9 from STROBE), how to handle missing data (items 12c and 12d from STROBE) and the description of additional analyses, such as subgroup or sensitivity analyses (item 12e from STROBE) (See Table S2 in Supplementary material). For instance, almost all publications have not described any effort to address bias (item 9 from STROBE), only five publications stated this (At et al., 2015; Chou and Leung, 2008; De Ronchi et al., 2005; Prina et al., 2020; Roquebert et al., 2018). For our purposes, publications missing the item 7 "Clearly define variables" and/or item 11 "Explain how quantitative variables were handled" from STROBE are of concern, because these items are particularly related to the operationalization of care dependency. Table S2 in Supplementary material reports the missing items from the STROBE list in each of the included publications.

Prevalence of care dependency

Prevalence of dependency was retrieved from 20 publications from which 10 used only Basic ADLs, 6 used Basic and Instrumental ADLs jointly, and 4 studies applied combinations of the

types of ADLs (See Table S3 in supplementary material for detailed data from publications reporting on the prevalence of dependency). However, the instruments are not necessarily harmonized and the studies were based on data from different regions, which may hamper the comparability of the result. As a result, we did not perform the meta-analysis of prevalence. For instance, the prevalence of dependency ranged from 4% to 24% for the studies using Basic ADLs and from 11% to 36% for the studies using Basic and Instrumental ADLs, showing the huge variability of the estimations. In terms of the quality of the prevalence estimation eight publications were classified with moderate risk of bias applying the modified Leboeuf-Yde and Lauritsen tool (See Figure 2 and Table S3 in supplementary material).

Figure 2. Prevalence of dependency



Discussion

Overall, our findings show that the operationalization of care dependency is heterogeneous. Inconsistencies have been observed in the identification of the need for help, in the instruments applied, in the type of ADLs and in each specific activity considered, and in the determination of severity of care dependency.

Despite this lack of consistency, the operationalization of care dependency has been done through explicitly formulating questions and/or answers that explicitly state the need for help in performing activities of daily living. However, a considerable number of publications identified care dependency only in the labels of the variables of interest, without explicitly mentioning or wording it in the questions or answers of the participants (Barragán-Berlanga et al., 2007; Castro and Guerra, 2008; De Ronchi et al., 2005; Fernández-Olano et al., 2006; Floriano and Dalgalarrondo, 2007; Gavasso and Beltrame, 2017; Giacomin et al., 2008; Lini et al., 2016; Maciel and Guerra, 2006; Rely et al., 2020; Rudnytskyi and Wagner, 2019). This latter operationalization may represent a proxy of the construct, as the need for help from others it is not directly assessed (WHO & WB, 2011; WHO, 2015). Although it has been argued that having difficulties in performing Basic ADLs could proxy care dependency (Kingston et al., 2018; Rodríguez-Sampayo et al., 2011), it is important that researchers explicitly acknowledge this when assessing the care dependency of older adults. Furthermore, inferring the care needs from moderate and sever disability could introduce considerably variability in the intensity of care required (Kingston et al., 2018) and, it would be desirable that research aimed at forecasting care needs explicitly identified it in the questions and/or answers to the participants. In addition, measures of care dependency consistent with the conceptual definition of the construct should collect information through questions and/or answers that contain in their wording the

requirement for help from another person (Harwood et al., 2004; WHO, 2015). As a result, it would be imperative that surveys of longitudinal studies of aging consider incorporating questions about the need for help in performing ADLs to be more accurate in future research about care dependency.

The heterogeneity in the operationalization of care dependency could be due to the information available in the existing surveys of aging. Future research could investigate the sources of information available worldwide on aging to relate them to the way in which care dependency is operationalized for community-dwelling older adults. This work could further investigate whether the available information allows for an adequate assessment of dependency, whether survey instruments are available, or whether comparison of results with survey information from different regions is possible.

Our work showed that several publications used recognized instruments, such as the Katz index, Barthel index or Lawton and Brody. However, only 13 publications have used these scales without modifications (Blanco-Reina et al., 2021; Cano Gutiérrez et al., 2018; Cortés-Muñoz et al., 2016; Floriano and Dalgalarrondo, 2007; Gobbens, 2019; Kessler et al., 2018; Maciel and Guerra, 2006; Muñoz Peñailillo et al., 2004; Oliver et al., 2012; Peter et al., 2022; Silva et al., 2019; Torres Buisan, 2004; Varela-Pinedo et al., 2015). Once again, the question is whether the modification of the instruments is due to the specific objectives of the research or to the information available in the aging surveys.

On the other hand, the publications included showed an overrepresentation of research conducted in low- and middle-income countries, since studies on aging have been extensive in developing countries in recent decades. This may be related to the important growth of the older adult population (Lima-Costa et al., 2016) but also to the implementation of long-term care

policies in these regions (Matus-Lopez and Cid Pedraza, 2016; Villalobos Dintrans, 2018). In particular, a large number of publications related to aging have been recovered using data from Brazil, as that country has experienced a very rapid rate of aging in recent years (United Nations, 2020).

It should be noted that in half of the publications the population analyzed included older adults aged 60 years or older, while in the other half they are people aged 65 years or older. Thus, a new effort must be made to have harmonized information on the definition of the older adult population to make international comparisons of both developed and developing countries.

We observed that researchers included different types of activities in their measure of care dependence, mainly Basic and Instrumental ADLs. This variability may assess different aspects of the construct and capture patterns of heterogeneity in aging trajectories (Marroig et al., 2022; Millán-Calenti et al., 2010). At the same time, it may pose a challenge for comparability and harmonization, so a balance should be sought between these aspects to improve research and the contribution to knowledge on dependency of older adults. In addition, it should be noticed that Instrumental ADLs may arise differences between men and women, responding to the gender division of tasks within the household. (Millán-Calenti et al., 2010). Finally, few studies have incorporated Advanced ADLs, which shows a dimension scarcely explored by research, which has been emphasized should be promoted (WHO, 2001).

Conclusions

Future studies of care dependency would benefit from explicitly mention the need for help from another person to adequately assess care dependence and the operationalization used should be adequately explained. In turn, studies on aging will benefit from adequate information,

considered in the current context, to assess care dependency in aging research to improve its understanding.

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