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Reverse retirement – a mixed methods study of returning to work in England, Italy and the United States: propensities, predictors and preferences

By *DEBORAH SMEATON*¹, *MIRKO DI ROSA*², *ANDREA PRINCIPI*² & *ZOE BUTLER*³

Abstract

Using methodological triangulation the study examines reverse retirement in Italy, the United States and England to explore the salience of cultural and structural factors and to consider the extent to which returning to work is a constrained choice. Analysis of harmonised panel data (HRS, ELSA and SHARE) indicates that reverse retirement is most common in the United States and extremely rare in Italy. In the liberal economies of the United States and England, financial factors are key determinants, including retirement income, having more children, children under 30 and mortgage debt. However, a certain degree of advantage is a prerequisite for returning to work, including higher education, good health, younger age, and free from caring responsibilities – opportunity structures and

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capacity to work therefore remain barriers for some older groups. Despite international convergence in the policy landscape, “retirement” continues to hold different meanings in the three distinct national contexts with implications for later life working.

Keywords: unretirement, reverse retirement, later life working, active ageing.

Introduction

Developed economies are facing a range of interlinked challenges associated with population ageing, declining male labour force participation and deteriorating support ratios (Hofäcker 2010; ONS 2016). These population developments have led to widespread skills shortages (CIPD 2012; UKCES 2014) and a feared pension crisis (DWP 2014a; Giarini 2009). In response to concerns that current systems will be unable to cope, governments have targeted key areas for reform, including social and health care, education, benefits and pensions. Employment among older workers is also high on the international policy agenda, with a range of policy incentives and deterrents implemented to prevent premature labour market exit before state pension age (SPa) (OECD 2015; WHO 2002). Working beyond SPa is also being encouraged as part of an “active ageing” agenda (European Commission 2014; Foster & Walker 2015; WHO 2002). The goals of “active” or “productive” ageing have been widely adopted across the Western industrialised world as a solution to the “problem” of population ageing, as exemplified in the following excerpt from a 2011 European Commission policy document: “We need to enable older people to make their contribution to society, to rely more on themselves and to depend less on others... Active ageing seeks to help older people to remain longer in the labour market” (EC 2011: 14).

There is a considerable body of evidence which highlights the complexity of retirement decision-making, but the range of policy levers and incentives which influence retirement trends are well understood and considerable international progress has been made in raising employment participation among the 50+ (DWP 2014b; Hasselhorn & Apt 2015). Less widely investigated is employment beyond SPa and studies which have addressed this age group have typically conflated individuals who

have continued working up to and beyond SPa with the same employer, that is, “continuers” with individuals who have retired, and then chosen to return to work, that is, reverse retirees¹ (Eurofound 2012; Klevmarken 2010; Larsen & Pedersen 2013; Parry & Taylor 2007; Reynolds et al. 2012; Smeaton & McKay 2003). The characteristics, motivations and employment determinants of these two groups are likely to differ.

Very few studies have focussed exclusively on reverse retirees (also referred to in the literature as “unretirement” – these terms are used interchangeably throughout this article), and given the scarcity of research there is a need to better understand the phenomenon. Insights are particularly important at this point in time given international moves to steadily increase SPa towards the age of 70 for men and women and the fact that increased participation rates over the past 10 years have primarily been a retention phenomenon with older workers remaining in their jobs for longer (Smeaton 2015). Understanding reverse retirement can help in the design of policies and incentives that might aid those seeking such a transition. Some individuals may have been forced out of the labour market due to redundancy, or may have experienced enforced retirement for health or caring reasons. Others may have voluntarily exited the labour market but found retirement did not live up to expectations. As circumstances change, opportunities to return to the workplace may be welcomed and measures to improve recruitment rates later in life are therefore warranted. There are concerns, however, that while the “active ageing” agenda promotes longer working lives on the grounds of health and well-being benefits (European Commission 2014; WHO 2002), withholding access to state pensions until age 68 or above may lead to hardship later in life as some groups of older people find themselves unable, despite economic need, to continue working (Macnicol 2010). Significant demand-side obstacles can also hinder unretirement; evidence suggests that while employers are now more willing to retain older workers and will take steps to maintain their employment, the impetus to recruit older workers has not increased to the same extent (Kidd et al. 2012); a number of studies emphasise the continued significance of age discrimination in the labour market (Porcellato et al. 2010; Smeaton & Vegeris 2009; TAEN

¹ It should be noted that many individuals who self-report as “retired” are below state pension age.

2013). Moreover, while the right to work as long as desired is valued, this freedom to choose is a hollow right insofar as financial necessity is a key determinant.

The few studies that have investigated reverse retirement, most of which are American in focus, have presented the transition conceptually as either (1) planned in advance and seen as part of an expected retirement lifestyle or (2) in response to a “shock” in retirement such as an unwelcome narrowing of social engagement, retirement not living up to expectations or inadequacy of finances (Cahill et al. 2010; Haider & Loughran 2001; Kanabar 2012; Kutlu-Koc 2014; Lahey et al. 2006; Maestas 2010; Petterson 2011). These studies consistently find a higher incidence of reverse retirement associated with being male, of younger age and in good health. Evidence relating to economic factors however is more mixed. Maestas (2010) finds that the probability of unretirement in America is unresponsive to declines in net worth or increases in medical expenses after retirement and that unretirement is largely a planned and anticipated event. Petterson (2010) observes, in the Swedish context, low financial incentives to re-enter the labour force post-retirement due to comparably generous social insurances, providing secure pension incomes; reverse retirement in Sweden is therefore driven by lower satisfaction with retirement and it is the higher educated and those on higher pension incomes who are most likely to reverse retire. Haider and Loughran (2001: 20) observe that it is the better educated and wealthier Americans who are most likely to work at older ages, going so far as to conclude that “work may be closer to leisure for the majority of elderly workers.” Similarly, in a study of English male retirees by Kanabar (2015), pension wealth was not found to have an effect on the hazard of unretirement, suggesting that sub-optimal retirement saving is not a driving force and that unretirement is, instead, a lifestyle choice. Other studies of later life employment have also noted that finance is not as critical a factor in work/retirement decisions as sometimes assumed (Hirsch 2003; Sass 2016) – some individuals actively choose a lower retirement income and will adjust consumption rather than continuing or returning to work. Giandrea et al. (2010) and Kutlu-Koc (2014), however, analysing the American Health and Retirement Survey (HRS), do find evidence of the salience of financial factors and that compared with the security of a defined benefit pension,

a defined contribution pension increases the incidence of unretirement as does lower wealth as measured by savings.

This study aims to contribute to the literature by means of an exploratory mixed methods and cross-cultural comparative approach, using a common analytical framework to investigate reverse retirement in three countries – England, the United States and Italy – to shed light on the influence of structural and cultural context and also to consider further the role of financial considerations. The study combines analysis of harmonised large-scale surveys to chart the incidence and determinants of reverse retirement with qualitative methods to present a more nuanced account of the motives and meanings of work, giving a voice to older, retired people.

Key research questions include: under what circumstances do individuals reverse retire (and how important is opportunity structure and cultural norms); and to what extent is reverse retirement a reluctant or constrained choice?

Choice of Countries

The three countries were chosen to reflect distinct economic and welfare regimes and cultural diversity. Public policies determine work opportunities, income and family responsibility constraints (reflecting provision of services); these different institutional settings might therefore lead to distinct opportunities within retirement and different plans for retirement lifestyles including orientations towards work. Two countries belonging to the same welfare regime (liberal) were selected to understand possible intra-regime differences, plus a country belonging to a different welfare regime in order to study inter-regime differences. Italy (a Mediterranean regime), was chosen to contrast with England and the United States given the notable difference in pension net replacement rates (much higher in Italy), potentially a key factor associated with decisions around returning to work.

Previous studies have demonstrated the value of cross-country analyses in highlighting the significance of economic incentive structures (Gruber & Wise 1999), welfare regime type (Hofäcker 2010) and specific policy measures (Blossfeld et al. 2006, 2011; Ebbinghaus & Hofäcker 2013;

Hofäcker et al. 2016) in explaining early retirement trends of the 80s and 90s and their more recent reversal. Key determinants they identify are nation-specific labour market regulations, systems of taxation, employment activation policies, employment protection legislation, pension systems and education systems. Many of these institutional incentives and disincentives may also have a bearing on whether an individual chooses or is able to return to work after a period of retirement.

Italy represents a Mediterranean welfare regime where the role of the family is central (Ferrera 1996). Childcare and eldercare are predominantly delegated to the family. Formal care arrangements are less developed with implications for the range of options facing older people as they enter retirement, as retirees become a resource for caring roles.

England and the United States represent a liberal welfare model, characterised by de-familialisation with a broader role for private care (Bambra 2004), which enables individuals to participate in society (work, volunteering and other activities) and be independent from the family (Esping-Andersen 1990, 1999). However, there are a range of policy differences between these two countries.

In England, it is not possible to draw a state pension before SPa, but the tax benefit and pension systems permit individuals to work while drawing state and/or private pensions, providing a financial incentive to continue working beyond state pension age. In 2006, age discrimination legislation was introduced and in 2011 the default retirement age was abolished so older employees are no longer expected to retire once they reach SPa. Other measures introduced to promote flexibility and thereby support later life working include the 2014 Flexible Working Regulations which extend to all employees the statutory right to request flexible working such as reduced hours, flexitime or working from home (although employers can refuse requests on business grounds).

In the United States, a variety of pro-work incentives has impacted older Americans since the early 1980s (Cahill et al. 2016). In 1986, mandatory retirement was eliminated for the majority of American workers. The full retirement age (FRA) of the public pension system, known as social security, has been increasing, but early access to social security is permitted, currently from the age of 62, with actuarial reductions. Other incentives include the delayed retirement credit (DRC)

and elimination of the social security earnings test for individuals who work beyond the FRA.

The source and value of pensions also differ between the three countries. Seventy-two per cent of Italians' pension is from the first pillar of state provision compared with 50% for the English and 38% for Americans. In the United States and England, pensioners are more dependent on occupational and private pensions as sources of income. In both the United States and England, occupational pensions have shifted dramatically away from defined benefit plans to defined contribution plans leaving individuals more exposed to both investment risk and longevity risk later in life, creating an incentive to work longer to insure against both (Munnell 2014). It should also be noted that average net replacement rates (the value of pensions as a proportion of average earnings) stand at 81% in Italy, 42% in England and 47% in the United States (House of Commons 2015). Health insurance costs prior to Medicare eligibility are a further significant consideration for Americans.

The 'methods and analytic approach' Section 2 sets out the methodological approach and analytical methods. The 'Results' and 'Work orientation – cultural context' sections sets out findings from the two strands of analysis, while the 'Discussion' section discusses the findings and raises policy implications.

Methods and Analytic Approach

In exploring reverse retirement, secondary data analysis techniques are used to model patterns of employment behaviour and examine the factors associated with returning to work. In addition, to gain deeper insight into attitudes towards and experiences of retirement, analyses of depth interviews are also undertaken. This form of methodological triangulation (Denzin 2006) allows for a more rounded understanding of the influences which may lead individuals to return to work or refrain from making such a transition.

Quantitative Methods

The quantitative data analysis uses three data sources: the *Survey of Health, Ageing and Retirement in Europe* (SHARE); the *English Longitudinal Study of*

Ageing (ELSA) and the American Health and Retirement Survey (HRS).² These longitudinal surveys collect information about health, employment, socio-economic characteristics and household circumstances among people aged 50+ every 2 years. Compatibility between data sources has been aided by the *Gateway to Global Aging Data* platform (<https://www.g2aging.org/>) which provides syntax for variable harmonisation.³ The main outcome of interest is whether individuals return to work after a period of self-defined full retirement (dichotomized into 0 if the subject remains fully retired and 1 if she/he returns to work by the next interview wave); therefore, logistic regression is used. Returning to work was defined using a variable which asked whether respondents had been in paid employment in the previous month. This approach is likely to underestimate the incidence of reverse retirement somewhat as individuals may have returned to work briefly between waves but then retired again.

Independent and Control Variables

Informed by the study's key research questions, the models are designed to examine the significance of financial constraints as "push" factors. In addition to retirement income, household circumstances, including the number and ages of offspring, may drive reverse retirement on financial grounds. Parents make sacrifices for their children well into adulthood, often providing support with higher education costs or helping children to get on the housing ladder. Having younger children, more children or children still living at home may therefore make greater demands on parents' resources. In England in particular both housing and education costs have escalated dramatically in recent years potentially influencing parents' work-related choices. Economic factors modelled include

² For more information about these datasets, see the following websites: <https://g2aging.org/?section=survey&surveyid=35> for the harmonised ELSA, <https://g2aging.org/?section=survey&surveyid=60> for the harmonised SHARE and <http://www.rand.org/labor/aging/dataproducts/hrs-data.html> for the RAND HRS.

³ In taking a harmonized approach, the study was unable to use some variables in the analysis that previous studies have indicated may be correlated with unretirement, in particular, the type of pension received (whether defined contribution or defined benefit). Occupational data were also incompatible as the three datasets used different classificatory approaches.

retirement income decile; income squared (to test for a possible parabolic relation with the outcome variable); number of children; having at least one child aged under 30; having children living at home; and housing tenure (still paying a mortgage, own outright, rent, rent-free/other).

Previous studies have also highlighted the salience of “linked lives” (Elder et al. 2003), pointing towards the synchronisation of retirement transitions among couples and the extent to which life decisions are taken in the context of wider family considerations. In addition to the indicators relating to offspring above, variables include marital status (couple, separated/divorced/widowed, single) and whether a partner is working.

Other covariates which can influence opportunities to reengage with the labour market include key resources such as health, education and volunteering in addition to gender, age and caring responsibilities. Health status includes self-reported health (excellent/very good; good; fair/poor) and an indication of any work-limiting health problems. Caring responsibilities are included as a potential obstacle to work (a binary variable indicating whether any caring duties are performed at least once a week). Performing a volunteering role (at least once a month) is also added to the model – volunteering activities can expand social networks, thereby exposing individuals to other opportunities (Gonzales & Nowel 2016) and, according to the role extension perspective (Hank & Stuck 2008), people active in one area will also be active in another. Education level (below tertiary; tertiary/secondary school level; above tertiary) is also likely to influence opportunities to work.

Qualitative Methods

The study seeks to complement the modelling evidence by introducing the voices of retirees. Drawing on interviews, this element of the study fleshes out the quantitative analyses by providing greater depth of insight in relation to whether and why people may wish to return to work after a period of retirement, and the type of job they are seeking.

The qualitative strand of the study is based on semi-structured interviews (conducted by the authors and senior research colleagues) with 133 individuals in England, Italy and the United States. Fifty-five were conducted across England (mean age at recruitment 61) 40 in Central Italy (mean age at recruitment 60) and 38 in North West United States

(mean age at recruitment 62). All interviews in England and Italy were conducted face-to-face in participants' homes, in the United States a combination of face-to-face and telephone interviews were conducted; they were typically of 60–90 minutes duration. Over a period of 3 years people were interviewed up to three times – at baseline while they were still in employment and then on two further occasions once they had retired. The interviews were conducted between May and September in 2014, 2015 and 2016.⁴ Issues addressed included work experiences; the decision to retire; and retirement activity, satisfaction and orientations. People were identified by a recruitment agency in each country on the basis that they were working at least 30 hours a week and planning to retire in the next 12 months. Respondents were sampled purposively with reference to; income level, gender, partnership status and age as these were anticipated to affect opportunity structures and attitudes. All interviews were digitally recorded (with interviewee permission) and transcribed verbatim. Data management and analysis was conducted using NVivo and MAXQDA to thematically code interview transcriptions, using both deductive categories from the literature and inductive categories arising from the data itself to develop coding frames, which were then used independently by coders and checked (e.g. for missing/overlapping categories and consistency in allocating data to particular categories).

Ethical issues were carefully considered at the outset of the study and, prior to data collection, approval from the host university's ethics committee was gained. All participants were given full information about the project and signed detailed consent forms prior to interview. All interview data have been anonymised and are held securely. To protect privacy, reference to participants below provides only basic information including age at wave 3, country of residence, gender and partnership status.

⁴ By 2014, a range of pension policy reforms, discussed above, had been introduced in each country, including age discrimination legislation in Italy and England, abolition of compulsory retirement in England and disappearance of defined benefit occupational pensions in England and the United States. Increases to state pension age were also underway.

Results

Reverse Retirement – Incidence and Determinants, Evidence from ELSA, HRS and SHARE

The incidence of returning to work in Italy, England and USA is shown in Figure 1. Reverse retirement is barely evident in Italy – the 2 year transition rate is just 2% among 50–70 year olds. Transitions to retirement in Italy would therefore appear to effectively be a one way street. Reverse retirement is not common in England but 6% made a return to employment from retirement. The two yearly incidence of reverse retirement is more common in the USA, at 10%.

Determinants of Reverse Retirement – Multivariate Regression Analysis

Table 1 sets out the results from logistic regression analyses. In comparing the three countries it is evident that very few factors achieve statistical significance in predicting reverse retirement in Italy, consistent with the rarity of this transition. The structural and cultural obstacles to reverse retirement in Italy are not challenged by financial need and the only significant predictors are age and gender. In all three countries, reverse

Figure 1. Incidence of “reverse-retirement” among 50–70 year olds by country

Source: HRS, ELSA and SHARE 2004–2012 pooled two yearly waves

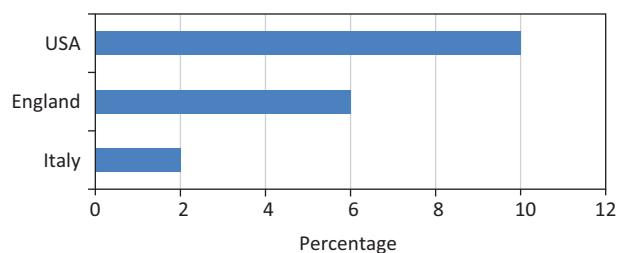


Table 1. Multivariate logistic regression – determinants of reverse retirement

Determinants	England	Italy	The United States
	<i>n</i> = 10,361	<i>n</i> = 2,852	<i>n</i> = 19,643
	<i>R</i> ² = 0.1755	<i>R</i> ² = 0.1670	<i>R</i> ² = 0.1356
	OR	OR	OR
Female gender (ref. male)	0.82**	0.39***	0.74***
Age band (ref. 50–54)			
55–59	0.66***	0.19***	0.66***
60–64	0.41***	0.11***	0.51***
65–69	0.33***	0.08***	0.39***
70–74	0.12***	0.05***	0.29***
75+	0.21***	0.01***	0.11***
Income decile	1.04	0.72	1.22***
Income decile squared	1	1.03	0.98***
Marital Status (ref. couple)			
Separated/divorced/widowed	0.62***	0.69	1.11**
Never married	0.69	4.42	0.74**
Education level (ref. no education)			
1–13 school years	1.12	0.88	1.1
14+ school years	0.85	1.21	1.25***
Health status (ref. excellent/very good)			
Good	0.95	1.34	0.82***
Fair/poor	0.56***	0.79	0.47***
Work-limiting health problems (ref. no)	0.79**	1.09	0.60***
Housing tenure (ref. paying a mortgage)			
own outright	0.58***	2.2	0.98
rent	0.69*	2.56	0.94
rent-free/other	1.13	-	0.79
Volunteer (ref. no)	1.39***	1.48	1.41***
Carer (ref. no)	1.12	1.39	0.90*

(Continued)

Table 1. (Continued)

Determinants	England	Italy	The United States
	<i>n</i> = 10,361	<i>n</i> = 2,852	<i>n</i> = 19,643
	$R^2 = 0.1755$	$R^2 = 0.1670$	$R^2 = 0.1356$
	OR	OR	OR
Partner employed	2.13***	-	1.14**
No. of children	1.09**	1.06	1.02**
At least one child age <30 (ref. no)	1.45***	-	-
At least one child living at home (ref. no)	-	0.88	1.09

*** $p < 0.01$, ** $p < 0.05$, * $p < 0.1$.

retirement is more common among men (particularly so in Italy) and the odds decrease progressively with age – consistent with previous studies.

In relation to financial factors, lower incomes do not increase the probability of returning to work in England but other economic factors do have an influence. Firstly, still having mortgage debt is associated with propensity to return to work. This determinant is not significant in Italy or the United States which may reflect the distinct British housing market. House prices in England have long been very high and continue to rise and it is therefore likely that mortgage debt is a greater burden. Secondly, having more children slightly increases the odds of returning to work, as does having a child under the age of 30 (plausibly due to the higher probability that they are still in education).

In the United States, income is a significant determinant, but the findings suggest an inverted U shape, so it is the middle-income groups who exhibit the greatest odds of reverse retirement (consistent with evidence from Giandrea et al. 2010). Having more children also increases the probability of returning to work.

Non-financial factors are also significant. Not surprisingly, health status is critical – the worse the self-reported health the lower the likelihood of reverse retirement, with similar findings in relation to having a work-limiting condition.

Being active in a volunteering role enhances the probability of reverse retirement in all three countries (statistically significant in England and the United States). Being active in the community in a voluntary capacity may therefore present opportunities for paid employment and reflect individual aspirations for retired lives beyond the domestic sphere.

Consistent with previous studies which have found that couples often synchronise their retirements, having an employed partner increases the probability of reverse retirement in all three countries (although not statistically significant in Italy).

Years of schooling and caring responsibilities are not predictive of reverse retirement in Italy or England (although it should be noted that the caring variable does not capture intensity of caring). For the US sample, by contrast, caring significantly reduces the odds of returning to work while higher education levels increase the odds, achieving statistical significance among those who attended college or university.

In summary, reverse retirement is largely associated in the United States and England with a certain degree of socio-economic advantage; enhanced odds are related to being in younger age groups, in good health, with an employed partner and, in the United States, higher levels of education. There is also evidence of financial push factors increasing the odds of unretirement. In England, this includes having a mortgage to pay off, having a larger family and having children under the age of 30. In the United States, higher income groups are less likely to unretire, with middle-income groups the most likely (low-income groups tend to have other health, education or employment history disadvantages which can act as a barrier to employment).

In Italy, the incidence of reverse retirement is so low that analyses, based on low sample sizes, struggle to detect significant effects. Therefore, findings only indicate that reverse retirement is associated with being a younger man.

Lifestyle Orientations among Recent Retirees

In the previous section, key socio-economic, demographic, family and health factors associated with reverse retirement were highlighted; these are representative of older populations but missing from the picture was a

sense of how individuals feel about and experience retirement, what their priorities are at this time of life and how working fits into their new lifestyles. Drawing on interviews with individuals in Italy, the United States and England who have transitioned to retirement, deeper insights at the level of meaning are presented in relation to motivations to work and reasons for shunning opportunities to continue along a path of “productive” ageing despite, in some instances, apparent financial need.

Being eligible for a pension (state, occupational or private) were key triggers for retirement timing among the qualitative samples of retirees. Many were also keen to stop working while still in good health and able to enjoy their retirement years. For others, retirement was simply described as “normal.” Job-related reasons for retirement were also prevalent such as stress, heteronomy, feeling worn out or commuting frustrations. Cited attractions of retirement in all three countries included spending more time with friends and family; more travel and leisure time; and freedom and time sovereignty. Summarising “orientations” towards retired life, several groups were identifiable across the three country samples (not mutually exclusive):

- **Creatively oriented:** A drive to be creative was common, with a broad range of interests including music, writing, photography, languages, theatre, painting, gardening and crafts. For many in this group, previous jobs, which they may well have enjoyed, did not provide a creative outlet, and retirement was therefore seen as providing an opportunity to explore new skills and interests or to return to passions which had been marginalised, in some cases decades ago.
- **Family and home oriented:** For many, working lives had squeezed the time available to spend with family and friends; retirement was seen as finally providing the opportunity to re-prioritise relationships and provide more support for family members.
- **Leisure oriented:** More frequent travel was one common aspiration as was the desire to pursue a wide range of hobbies, sporting or other physical activities (such as walking, golf, bowling and dancing) – motivated by a desire to maintain or improve health once retired, as a useful means of occupying newly freed time and as a good source of social activity.

- **Work oriented:** This group wished to maintain the structure and/or social engagement provided by employment and continue to use their skills. For some, this orientation also reflected perceived financial need whether for basics or for “extras.”

Differences in the dominance/prevalence of each of these retirement orientations were evident when comparing retirees from each of the three countries, reflecting both cultural variation in relation to values and also distinct welfare regimes shaping the opportunity structure facing individuals at this stage of their lives.

Focussing on work orientation, there are clear differences among the three country samples, highlighted in Table 2. By wave 3 of the interviews, just one Italian had returned to work within 2 years of retiring (a further six expressed a desire to find some sort of a job but only one was actively searching, the remainder observed they had found no opportunities). Several Italians also expressed disappointment that their employer had denied them the opportunity to phase their retirement by means of a period of part-time work. At the other extreme, most of the American sample either continued to work despite stipulated intentions to retire, unretired soon after leaving a career job or expressed a desire to find work. The English sample fell between these two extremes – of

Table 2. Retirement trajectory and aspirations – outcomes by wave 3

	Italy	England	The United States
Did not retire, continued working full time	0	6 (13%)	7 (24%)
Phased retirement (reduced hours with same employer)	0	2 (4%)	4 (14%)
Reverse retired	1 (2%)	11 (23%)	6 (21%)
Retired but would like to re-enter the labour market	6 (15%)	5 (11%)	7 (24%)
Retired with no desire to return to work	33 (83%)	23 (49%)	5 (17%)
Total N	40	47	29

47 interviewees at wave 1, 6 did not retire after all by wave 3 (usually citing financial reasons for their changed plans), while 2 continued working on a part-time basis and 11 reverse retired. Half the English sample (49%) had retired by wave 3 with no wish or intention to return to work – a proportion which is somewhat under half that of the Italian sample (83%) but three times higher than the American sample (17%); a pattern broadly reflective of the survey-based evidence above.

Overall, the reverse retirees had much in common – they were all working locally; typically working far fewer hours, often on a flexible basis (e.g. a nurse who returned to an NHS nursing “bank” and worked two shifts per month); and most were in jobs with low entry barriers (e.g. low-skilled driving jobs, bar staff or in the retail sector); or they were exploiting skills they had developed over a life time, often on a self-employed/freelance basis (e.g. a heating engineer who became a self-employed plumber, an electrician now a self-employed odd job man and a retired reverend who now conducts occasional freelance funerals and weddings). Employment transitions and motivations for returning to work (which usually involve multiple reasons) are shown in Table 3. Several of the reverse retirees are above state pension age, including a 73-year-old. Their average age, however, is 63 which is comparatively young (below state pension age), consistent with the quantitative evidence cited above which finds the risk of reverse retirement decreases with age.

Analysis of retirement narratives was conducted to better understand differences in work orientation and associated satisfactions with retired lifestyles.

Italians: family orientation and retirement as rest. Retirement was perceived by the Italians as a clearly demarcated phase of life with a strong expectation among both men and women that either a caring role or a strongly family-oriented lifestyle would be adopted. While some identified caring responsibilities as an obstacle to specific aspirations, on the whole, formal caring or a voluntary transition into a family support role was unquestioned and absorbed into life providing a sense of meaning, commitment, structure and a source of pleasurable relationships. One Italian woman typified this reorientation towards the home and family, and described taking on a “housewife” role in retirement:

Table 3. Reverse retiree characteristics and job transitions

Gender and age (wave 3)	Pre-retirement job	Post-retirement job	Post-retirement contract	Motivation
<i>American sample</i>				
US02, F, 60	Receptionist	Clerical work	Temp employee	Financial
US18, M, 67	Real estate broker	Real estate	Self-employed	Financial and for stimulation
US24, F, 61	School counsellor	Manufacture and sale of beauty products	Self-employed	Fulfillment
US26, F, 64	Retailer	Refurbish furniture and Uber driver	Self-employed	Financial and social
US29, F, 63	Distribution centre manager	Sales representative	Employee, PT	Financial and social
US40, M, 66	Builder	Surveyor	Consultancy (30 hours per week)	Stimulation, so- cial and to keep active
<i>English sample</i>				
UK03, M, 62	Teacher	Exam invigilator	Zero hours contract	To ease transition
UK16, F, 61	Office manager	Bar job	PT employee	Social
UK20, M, 73	Central heating site manager	Plumber	Self-employed	To keep active
UK21, M, 68	Driver	Minibus driver	Self-employed	To get out of the home
UK34, M, 63	Engineer	Project work for ex-colleague	Freelance	For stimulation and the "wel- come cash"

(Continued)

Table 3. (Continued)

Gender and age (wave 3)	Pre-retirement job	Post-retirement job	Post-retirement contract	Motivation
UK36, M, 67	Electrician	Odd job man plus 1 day a week electrician for son-in-law	Self-employed	To keep busy and favour for relative
UK42, F, 57	Nurse (night shifts)	Nurse (day shifts and different role/responsibility)	Bank work, 0 hours contract; 2 shifts a month	Finance, and for some structure
UK41, M, 62	Union manager/official	Local government councillor	1 day per week, expenses only	Stimulation, interest in politics
UK56, F, 65	Nurse	Nurse (new role and status)	Bank work, 0 hours contract; 1 shift per week	Financial
UK70, M, 59	Carpet fitter – employee	Carpet fitter for son-in-law	Self-employed for 6 months only	A favour for a relative
UK71, M, 67	Reverend	Freelance funerals and weddings	Self-employed	For pocket money and to keep active
<i>Italian sample</i>				
IT20, M, 57	Petrol pump attendant	Estate agency tasks	Occasional basis, cash in hand	Helping a friend, for the extra money and variety of life

Now you try to do more for the family, to better look after the home, which, inevitably, had previously been neglected. So, now the most important thing for me is my family... I now have time to devote to myself and to my loved ones. (IT36, F, Age 60, lives with husband)

In comparing the three samples, of note was the extent to which Italians discussed the positive aspects of their retired life in very traditional terms of "relaxation," being "calm," using terms such as "serenity," "rest" and "tranquillity," expressing pleasure in living at a slower pace, napping and being more contemplative, with one retiree now never wearing a watch. This perspective could also be found among some of the English and American retirees, but "retirement as relaxation" was most dominant among the Italians who appeared culturally to regard the role of "pensioner" favourably, as a time to embrace a more sedate lifestyle as can be seen from the following quotes describing retirement:

Sweet doing nothing, I appreciate it. (IT07, F, 61, lives alone)

I do things more slowly, I'm not in a hurry anymore ... In general, my pace is slower, it is different now ... this sense of freedom is very beautiful. (IT17, F, 68, lives alone)

I have more time to reflect. An expression used by my father when he retired comes to mind: "you run, run, run, but for going where?" It's true. I enjoy little things... My pace of life is more relaxed, I'm doing a lot less than before. In short, it is important also to live with idleness. (IT21, F, 59, lives with husband and daughter)

The positive aspect of retirement is that I can be tranquil. (IT27, M, 61, lives with wife)

Over half the Italian sample valued their retired lives in these terms which was somewhat at odds with the principles of "active" and "productive" ageing, which emphasise the importance of "active" lives, "giving back" and are in tune with the "busy ethic" as expounded by Ekerdt (1986) who observed normative expectations that old age should be filled with activity. Exhortations for busy, active and productive retirements may therefore be culturally biased insofar as they appear consistent with the practices and expressed preferences of older Americans in particular but differ somewhat from descriptions of what represents a good life among the retired Italian sample. Although not all Italians were happy with retirement, some talked of monotony and being unhappy with

various aspects of their lives, but very few saw opportunities to return to work as a solution to their dissatisfaction.

The Italians were also rather stoical in relation to money. While it was acknowledged that income may at times be tight, there was a sense that family, good health and freedom were more important than money. The Italian propensity to adapt to lower incomes rather than seek to earn more is captured in the following quote from an Italian woman:

I will not have enough money but I do not mind! If I have spent my money by the first day of the month and I have to wait until the 10th to receive my pension, what shall I do? I will check what we have available in the refrigerator... If I do not have fuel in the car I will not use it... But I will not start working again! (IT26, F, age 59, lives alone)

Americans: work orientation and retirement as a time for new challenges The Americans were more likely to see retirement as a new beginning, with opportunities for fresh challenges. They remained oriented towards work and were the least oriented towards leisure – reflective of the strong work ethic of Americans identified in previous studies (Nimrod et al. 2007, 2008). One American woman in her late 50s was asked whether she saw herself as retired now that she had left her teaching post and was drawing a generous pension, to which she responded:

No, I don't think I do. I think of it as the next step in my life, doing something different. (USID20, F, age 59, lives with husband)

The following interview excerpts similarly exemplify “retirement” as a time for change or new opportunities rather than as a one way exit from work:

Creative people don't retire, they may stop working but that's not retiring. (USID23, M, age 73, lives alone)

I'm looking forward to doing something different. I have not yet decided what that might be. But I am looking forward to the challenge. (USID38, M, age 64, lives with wife)

I don't know whether you ever totally retire. I mean I don't plan to. I retired from my career for now. I'm going to be doing something else I'm just not sure what. (USID13, F, age 67, lives alone)

Many were leaving career jobs and taking their pensions because they wanted to channel their energy differently, towards more meaningful work, better work-life balance or just for a change. Receipt of a pension provided people with the financial means to make changes and exercise choices based on shifting preferences. As found in other research, retirement among Americans was perceived as a “second act” in pursuit of new challenges rather than a “second childhood of boundless leisure” (Moen 2005: 203). This employment orientation is also consistent with evidence from Maestas (2010) who concluded that in the United States unretirement is largely anticipated in advance and not a result of financial shocks or poor planning.

Dissatisfaction with retirement was a further motivation for working, and one of the main sources of discontentment was the view that there were too few opportunities for social engagement and a lack of community that might facilitate casual or more regular social contact. This perception could also be found among a minority of the English and Italians, but was more prevalent among the Americans, many of whom talked of feeling lonely or isolated and the difficulty of making friends and finding people to “play with.” Americans were particularly receptive to the idea of retirement groups (whether workshops, social groups, drop-in centres or similar) with two-thirds of the sample expressing enthusiasm for this kind of social support. Most Americans had sought and received financial advice prior to retiring but noted a vacuum in relation to non-financial support.

Given social engagement deficits, reverse retirement had a very beneficial transformative effect for one 65-year-old American man who, having retired, described his subsequent decrease in social activity and in activity more generally; he was not motivated by any passions or interests nor socially active and so spent his days reading and napping. During this time, he put on weight partly due to his diet which had deteriorated, especially in the evening with excessive snacking due to boredom. By wave 3 he had secured a new job:

I took it on because I was finding myself being bored and even less active and I didn't feel as much of a connection with anything because I have a fairly limited friend base, most of my adult life has been either home oriented or work oriented and having it be totally home oriented, I was finding that unsatisfactory. So I went back to work and this fulfils a number of criteria. (USID40, M, age 66, lives with wife)

While evidence from some previous studies indicates that unretirement is not associated with financial need, the American sample of respondents did stand out as distinct in exhibiting a more general anxiety around money. In these instances, retirement income was often perceived as adequate with financial safety nets in the form of savings in place, but, having spent their lives conscious of the need to save and prepare, combined with uncertainty around how long resources would need to last, money was a constant source of worry. Financial concerns prompted a return to work in the following example of a woman with savings and a household pension income of around \$7000 per month (excluding earnings from a part-time job):

I do have financial reasons to want to continue ...like you can't count on your stock market or even compound interest might be your friend but not with the interest rates we have. I think that financial planning is so critical ... having saved everything they need financially to last them the rest of their lives, I don't see how anybody. I mean I don't even know if Donald Trump would have enough money, you know, at a certain point to say "okay I've got all I need...." (USID28, F, age 64, lives with husband)

One 67-year-old American woman who was receiving \$2100 per month described her decision to return to work in order to continue earning almost as a moral imperative, despite being "tired of working" she observed:

You're supposed to earn all the money you can in your life while you can. (USID35, F, age 67, lives alone)

English: leisure orientation and retirement as a patchwork of activities The British sample, in many respects, present a hybrid picture. There was a distinct subgroup who remained work oriented, but broadly speaking the English retirees could be described as predominantly leisure oriented.

Gardening was a particularly popular source of pleasure during retirement for the British – a creative activity that occupied long hours for both men and women, especially in the summer, providing a creative outlet and a key source of physical activity. Although some Americans and Italians were similarly enthusiastic gardeners, the lower proportions engaged in gardening activities reflect differences in housing in the three

countries. More of the English sample lived in homes with gardens – consistent with wider population level accommodation profiles.⁵

Compared with the Italians, the English were more resistant to full-time homemaker roles; although family was a strong orientation for many of both the American and English samples, it differed somewhat in intensity. In relation to grandparenting, for example, some respondents felt they had done their bit, really enjoyed being grandparents but did not wish to be relied on as formal carers, as in the following example of a man who hoped to spend his retirement years free of constraints in order to travel:

I don't know why but when you're grandparents and you're at home and they know you're at home, "oh, by the way, could you just look after so and so for the day, or a couple of days"... but like I want to do things, I've had my children, it's their job now. I don't mind occasionally but [not] weeks at a time because of holidays. (EN17, Male, age 59, lives with wife)

Similarly in relation to eldercare, several of the English sample were caring but on a drop-in or remote support basis. As one English woman noted, as much as she loved her parents she was not going to sacrifice her life to perform a caring role:

My dad is eighty-seven and my mum is eighty-six [but] we are not going to become the main carers. They'll have to get carers in and we'll just keep an eye on them, because I do know people work all their lives then either have grandchildren to take to school and pick up and things like that and older parents as well... We are determined that they can pay for their own care and we'll just prop them up. (EN43, F, age 60, lives with husband)

Among the work-oriented subgroup, a desire for considerable flexibility was evident. Where the prime attraction of retirement is time sovereignty and the ability to be spontaneous, reduced hours do not provide the degree of flexibility desired as part-time jobs still require a regular commitment. In the following example, it is evident that leisure is prioritised over work:

⁵ A total of 53% of Italians live in apartments/flats compared with 34% across the United States and just 18% in England (Eurostat 2014; Cox 2011).

I don't really want to be tied down to anything too rigid because I do want to travel, it might be that I can find something that I could do one day a week for six months and then have six months off to then travel or do a couple of months at the beginning and then have a block off and then a couple of months (UK42: F, age 54, lives alone)

Zero hours contracts could meet the flexibility needs of these retirees. Although widely criticised as depriving people of employment rights, security and financial stability, these are not the job characteristics which older workers are necessarily searching for. One 58-year-old English man had found a highly flexible opportunity which he felt would work well and allow him the spontaneity he strives for:

...if there's no work then I don't go, simple as that, that's how I want it, very flexible. They have a bank of people so they're ring me up and say "Do you want to come up Monday help out?" and I'll say "Sorry, no, I'm going shopping with the wife" ... "Okay no worries" and they'll ring somebody else so it's quite easy going. (UK67, M, age 58, lives with wife)

These individuals differed somewhat from the Americans by seeing themselves primarily as retired but would appreciate and benefit from opportunities to work sporadically. The evidence calls into question the utility or accuracy of the term "reverse retirement." Most of the returners regard themselves as primarily retired and saw their jobs as supplemental – part and parcel of their retired lives. A more accurate description of the phenomenon might therefore be "working in retirement." The Americans were less likely to describe themselves as retired on re-entering the labour market.

Work Orientation – Cultural Context

Structural, cultural and historical reasons account for some of the differences between the three countries in terms of their values, perceptions of retirement and orientations to work at this stage of life. Employment opportunities are few among older Italians; in order to claim a pension, it is first necessary to withdraw from the labour force; there is a pervasive early retirement culture; and with high youth unemployment older workers feel it is their moral duty "to step aside" to the benefit of younger generations. In contrast, an emphasis on the right to work

has a strong history in the United States where abolition of compulsory retirement and age discrimination legislation were introduced in 1986. For England, such developments have a much more recent history – age discrimination legislation was introduced in 2009 with abolition of compulsory retirement in 2011. England is thereby in a process of transitioning away from retirement as a clearly defined status transition towards a notably more blurred demarcation, in other words it occupies a middle position between the Italian and American regimes.

A further characteristic of working lives that may have explanatory power in terms of cultural context is the strong American “work ethic” as measured by working hours (whether by choice or constraint). Table 4 highlights the differences between each country in terms of hours worked and vacation time with potential implications for how readily each group might transition and adapt to a traditional retirement of leisure. Americans stand out as having notably less leisure time throughout their working lives given longer weekly and annual hours and fewer vacation days. Americans work an extra half a day every week and 366 hours more per year than the British and the Italians. This equates to an additional 9 weeks of work every year (assuming a 40-hour week) – a discrepancy which is explained in part by longer working weeks but also by the fact that Americans take 2.7 weeks less vacation time than the British and 4.1 weeks less than the Italians. At the very least, these figures imply that, on average, Americans may be less prepared for a life of leisure than their European counterparts.

Table 4. Work and leisure – all ages

	Italy	England	The United States
Average weekly hours worked	37.3	37.5	41.3
Average annual hours of work	1536	1530	1896
Holidays and vacation weeks taken	7.9	6.5	3.8

Source: OECD, *Society at a Glance 2009*, special focus measuring leisure.

Discussion

This article contributes to the small literature base which has examined the phenomenon of reverse retirement. The study set out to consider the circumstances under which individuals reverse retire; the significance of economic context, welfare regime, opportunity structure and cultural norms; and the extent to which reverse retirement reflects a reluctant or constrained choice.

Reverse retirement is not evident in Italy where retirement is still perceived as an earned right to be free from work, in part to make way for younger workers in a context of very high youth unemployment and supported by adequate public welfare provision with comparatively generous pensions. Italian narratives of retirement revolve strongly around traditional conceptions of winding down and playing a more dominant role in the lives of their families. This distinctive Italian attitude is consistent with findings from previous research which has highlighted that satisfaction among Italian retirees is more strongly associated with solid support networks and less with economic well-being (Ferring & Wenger 2003; Polverini & Lamura 2005).

In contrast, the normative ideal of retirement as an earned liberation from work would appear to have a weaker hold in the United States which is characterised by considerable diversity in the transition to retirement – including a widespread incidence of phased retirement, bridge jobs and semi-retirement (see Cahill et al. 2016), and a more ambiguous lay definition of retirement which is less bound to ideas of legitimised freedom from work. “Productive” ageing and remaining engaged in the labour market during “retirement” was found to be a common aspiration.

England seems to be moving towards the American retirement paradigm as ideally characterised by a patchwork of activities cutting across multiple life domains (family, work and civil society) but could still be characterised as having a foot in both camps.

Notions of “successful” or “adaptive” ageing as people enter and progress through their retirement years have been recognised as culturally contingent (Chung & Dodder 1996; Dein & Huline-Dickens 1997; Nimrod et al. 2008; Torres 2003), and findings from this study affirm the significance of context dependency. Using a cross-cultural and mixed methods approach, the study has highlighted considerable variety in retired

lifestyle preferences and complex decision-making in relation to working in retirement. Despite international policy convergence around the extended working life agenda, the meaning of retirement, lifestyle orientations and the role of work in retirement were still found to be quite distinct in Italy, the United States and England. A one-size-fits-all policy agenda, such as the normative goals of “active” or “productive” ageing, may be seen as a useful antidote to traditional conceptualisations of retirement as a time of disengagement and decline but risks an overly homogenised and prescriptive expectation of later life. Further research would be valuable, to include a wider range of countries (and regime types), to better inform Europe-wide policies (and beyond) designed to improve the experience of retirement as retired populations swell across the developed world. In addition to evaluations of the impact of different international labour market and taxation policies (reflecting distinct welfare regimes and political priorities), further research drawing on the voices of older people are also warranted to ensure that the needs, concerns and aspirations of older people are taken on board in policy formulation.

In relation to the economic push versus lifestyle choice debate, previous studies have largely concluded that financial factors do not typically play a significant role in reverse retirement decisions which reflect instead a voluntary retirement lifestyle choice. A more complex relationship between financial factors and the decision to return to work emerged from this study, arising from the methodological triangulation approach.

In Italy, cultural norms, a challenging economic environment and workplace policies combine to erect significant barriers to reverse retirement regardless of individual financial need. In the English context, although retirement income levels are not associated with unretirement, there are indications of wider financial considerations being relevant including outstanding debts and having children under the age of 30; depth interviews also surfaced financial motivations existing alongside other considerations (social in particular) and decisions were rarely mono-causal. In the American context, the highest earners were least likely to unretire, while middle-income groups exhibited the highest propensity to return to work and depth interviews revealed that a strong financial anxiety often underscores decisions to return to work even among the more affluent. American retirees were also pushed back into work disappointed with opportunities for social engagement – consistent with

earlier studies which have found disappointment with retirement to be a determinant of work returns (Lahey et al. 2006) and reflective of research by Patacchini and Engelhardt (2016), which found that the size and density of American's social network declined in retirement. However, while financial push factors and retirement disappointments were clearly identifiable, interviews revealed a more complex picture as employment was often described by the Americans in positive terms, as a new challenge or a new phase of life.

Combining the distinct methodologies enabled the study to highlight the interplay between cultural and structural factors. For example, in Italy there is little reverse retirement – explained in part by generous pensions and workplace polices, but interviews also surfaced a distinct culture which regards retirement as a deserved rest from work combined with opportunities to adopt new valued roles (carer, parent and grandparent). Similarly, comparing England and the United States, in both countries there is far more individual responsibility for pension adequacy; economic factors therefore represent a strong potential motivation to continue working. Yet, survey-based evidence reveals distinct patterns of work in the two countries – the qualitative evidence provided additional insights, indicating a dominant leisure orientation towards retirement in England, while a work orientation remains a strong cultural characteristic among the Americans.

The study also raised concerns around equality of opportunity later in life. On the whole, those with greatest financial need are also the most disadvantaged in terms of health, education or patchy employment histories (including women who have raised families) – these are key barriers to working. To the extent that unretirement is largely related to advantaged circumstances, capacity and opportunity constraints act to prevent reverse retirement from being a viable solution to poverty in later life.

The findings have a number of policy implications and raise questions around how working after retirement is conceptualised. Policies to enable and encourage reverse retirement in England in particular would be well advised to take on board evidence of a shift in preferences and orientation towards qualitatively more flexible arrangements. There is a clear demand for very flexible contracts, such as zero hours or short-term project work. While research has highlighted the importance in later life of a balance between discretionary time (leisure) and committed time

(work, volunteering and caring) for optimal well-being (Jun 2014), the preferences of many reverse retirees in this study strongly point towards an aversion to commitment in the sphere of paid or unpaid employment. Many of these retirees explicitly resisted the idea of paid work or volunteering, even on a part-time basis, on the grounds that it required a commitment they were unwilling to give.

Policies should not only address employment opportunities and flexibilities but should also focus on a broad range of support for those in retirement given that provision for the retired in many locales, across each of the three countries, seems weakly developed. Retirees highlighted too few opportunities for social engagement and community life and a lack of basic information advice and guidance that might smooth what is potentially one of the most challenging life transitions individuals make. A desire for workshops, drop-in centres, networks of support and other provisions was widely expressed and described succinctly by one 59-year-old Italian woman who spontaneously described what would have helped her transition: "There should be something for us pensioners ... they should give us a Guide for services for older or retired people. I would like something for those who are retiring, to help prepare for hobbies, or interests ... orientation courses, strategies to apply just before the transition to retirement. Yes, a guide to help us to psychologically and concretely prepare for retirement."

Finally, given the extent to which reverse retirement is associated with more advantaged circumstances, the policy shift towards extended working lives would seem to carry a risk of insufficient protection for some groups and an exacerbation of inequalities in older age. Significantly delaying state pension ages will have adverse consequences for those unable to continue working despite being most in need of opportunities to earn - implications for dignity in later life therefore emerge and policy solutions are needed, including the possibility of greater flexibility in accessing state pensions.

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Doing gender and age: The case of informal elderly care in the Czech Republic

By *RADKA DUDOVÁ**

Abstract

This article seeks to describe and explain some of the factors behind the prevalence of women in informal care for seniors. It presents a qualitative study of women who are caring for a frail elderly parent in the Czech Republic. Care is seen as a space where gender and other intersecting identities are performed and this has specific subjective, structural and material consequences. The author draws on biographical interviews with women caregivers and shows how they “do gender and age” in their narratives of how and why they made the decision to provide care and how they actually provide care. The author identifies situations and circumstances in which gender categories and gender relations shift and are destabilised by changes in society. The Czech Republic is a country with a history of state socialism and with traditionally large numbers of women in the workforce, but it also has a highly traditional gender culture.

Keywords: age, elderly care, gender, informal care, women.

Introduction

Despite some differences that derive from disparate welfare-state regimes and policy mixes (Bettio & Verashchagina 2012; Katz 2009; Naldini et al. 2016),

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around the world (even in the most affluent countries) most elderly care is organised within the family (Guberman et al. 1992; Suitor et al. 2011). Elderly care is moreover deeply gendered, in terms of both who receives care and who provides it. Women – daughters, daughters-in-law, wives and sisters – continue to be the main providers of informal care for the elderly at home (Bracke et al. 2008). Recent data indicate that this is equally true in the Czech Republic (see Dudová 2015a; Klímová Chaloupková 2013; Přidalová 2007).

In this article, I try to shed light on some of the reasons why most (family) care for the elderly is provided by women, and to this end I draw on biographical narrative research that I conducted among women caring for an elderly parent in the Czech Republic. The Czech Republic is a post-socialist country, where the availability of formal care services is limited and trust in institutional care is low, but where there is also a long history of a relatively high level of women's participation in the labour market. Most elderly care is provided at home by (female) family members. Until they retire, working women have to juggle work and a job with their role as a caregiver. This article looks at women's narratives of how and why they decided to care for an elderly parent and at the actual care work they perform in order to analyse how women caregivers "do gender" in care. The aim is to show how elderly care is gendered and to explain some of the factors behind the prevalence of women in informal elderly care in the context of a country with a familialist welfare state, but where there is also a high rate of women's employment. What positions do women occupy in the discourses and practices of care? What social structures do they thus (re)produce, and how do these structures determine their available positions and choices? I set to show that instead of just doing "gender," women caregivers do "gendered age," which may have important consequences for the future of elderly care in the Czech Republic.

Context

According to data from the longitudinal SHARE study, the Czech Republic, along with Poland, has the largest share of elderly care that is provided informally, that is, outside an institution, in Europe: 97% of the occasional care needs and 78.5% of the daily care needs of elderly persons

are attended to by family members or friends (Bettio & Verashchagina 2012). Data from a representative study of the Czech population aged 25–60 years (Lifecourses 2010) conducted in 2010¹ indicate that it is primarily women who provide informal care – both personal everyday and occasional care – for elderly family members. Women make up 80% of primary caregivers, that is, caregivers who attend to daily hygiene and feeding needs. According to the SHARE Wave 5 (2013) dataset, men also care for elderly family members, but they provide care with less frequency and the form of care is less intense, and their role in caregiving tends to decrease as a seniors' care needs grow (Dudová & Vohlídalová 2018).

During the state-socialist era (especially in the 1960s and 1970s), Czechoslovakia introduced different kinds of residential care facilities for the elderly and a system of home-help care services. However, in the 1980s, residential care facilities only had the capacity to accommodate the needs of 15% of the population aged 80+ and professional home-care services met the needs of another 20% (Maříková & Plasová 2012). After the political shift in 1989, the availability of residential care facilities decreased. Although since then the number of places in residential care facilities has been steadily increasing, the share of the demand for institutional care these facilities are able to meet has fallen further (to 10% of the 80+ population), while the number of rejected applicants for residential care has soared. The first government measures aimed at supporting informal family care were introduced back in the 1970s, and as the economy was liberalised in the course of the 1990s and 2000s, the state gave priority to family-based elderly care. The opinion that formal care services should only be used if there are no informal providers, that is, family members, to provide care, or if they fail to do so, is now widely shared by policy-makers, experts and the public (Dudová 2015a). In 2006, the care allowance for caregivers that was introduced in 1976 was replaced by a new allowance that is much higher and is paid directly to care recipients so that they can buy care services or pay a family member to provide care. Only about one-third of the recipients of this care allowance use it

¹ The Lifecourses 2010 dataset consists of data on 4000 respondents aged 25–60 years, forming a representative sample of the Czech population in terms of the standard quotas for survey-respondent characteristics (set for gender, age, size of the place of residence and region).

to pay for formal care services; the rest rely exclusively on care provided by family members (National Strategy 2016: 16). Currently, only one-fifth of elderly persons in need of everyday care live in residential (health or social) care or use formal (professional) care services provided at home (Nešporová et al. 2008). The rest receive informal care provided by family members; there is, however, no law that makes adult children legally responsible for attending to the care needs of their elderly parents.

The Czech eldercare system is a system in flux. The reform of the system in 2006 envisioned the formation of a quasi-market in elderly care. According to Sirovátka and Válková (2017), this reform was an exemplary market failure. While the declared objective was to widen the range of social services on offer and to encourage the development of domiciliary care instead of residential care, this did not happen, mainly because of the poor implementation and funding of the reform. This has since led to a decrease in the availability of public care services that have not been offset by the emergence of services in the private sector: 46% of the providers are public and 47% are non-profit organisations and churches, and about 7% of service providers are private and profit-oriented. The same public funding rules apply to all registered services regardless of what organisation or institution is providing them (National Strategy 2016: 33, data from 2012).

Unlike elderly care, childcare services (for children older than 3 years) have been able to provide almost universal coverage of childcare needs since the 1960s. This has made it easier for women to be a part of the labour force. Nonetheless, in the case of children up to the age of 3 years, coverage has decreased since the 1990s to the point where less than 3% of children aged 0–3 years are in childcare, while parental leave has been extended to 4 years. The long career breaks women must take to care for young children negatively impact their position on the labour market and reinforce the traditional division of labour in the family (see e.g. Saxonberg & Sirovátka 2006). According to the typology of welfare states developed by Saraceno and Keck (2011: 373–374), the Czech Republic belongs to the type of countries that support familialism (offering care leaves and allowances to family caregivers) and where publicly funded long-term care services are not widely available or affordable.

The issue of care provision has become controversial internationally as women's employment rates have increased and they have become

unwilling or unable to perform care and other household work the way they did in the past – without visibility, recognition or support from other actors in society (see Jacobs 2003). In the Czech society, the “refamilialisation” of elderly care has occurred in a situation where women’s participation in the workforce is high – and has been high since the 1960s. The share of working women among all women of an economically active age rose sharply from 55% in 1949 to 73% in 1959 and soared to more than 85% in the 1970s and the 1980s, majority of them working full-time (Křížková & Vohlídalová 2009: 39, 47). At the same time, the retirement age for women remained comparatively low, ranging between 58 and 63 years of age for women born in 1956, depending on the number of children they had – a woman who had raised two children could retire at age 60. However, the retirement age is gradually being raised and is higher with each cohort; a woman born in 1966 who has two children will retire at age 65. Women may thus be facing contradictory expectations as they enter the “third age” (see Dudová 2015b; Laslett 1991): they have to keep working for as long as possible but are also expected to care personally for elderly relatives.

The Czech Republic is a post-socialist country in the Central-East European region, and within this region it is the country in which the post-1989 economic transformation and the accompanying process of refamilialisation has had the strongest impact on gender (see Hašková & Dudová 2017). The Czech Republic can thus serve as a good example on which to demonstrate the different kinds of consequences that arise from the connection between femininity and elderly care (or from the construction of femininity in the practices and discourses of elderly care). In this context, where there is a high rate of women’s employment, but also a very traditional gender culture, women piece together their life stories using contradictory repertoires.

Theoretical Background

There are a number of theories that seek to explain the prevalence of women in long-term care for seniors. These explanations refer to the role of early gender socialisation, structural factors (the socially determined gender division of labour, inequality in the labour market and in society in general), emotional bonds and close relationships (between a mother and daughter),

the preference for care from a child of the same sex (and mothers, as women, tend to live longer) or the different gendered normative expectations about the obligations of intergenerational solidarity. All these explanations are relevant. Yet, in the light of the empirical evidence on the great range of care practices that exist, they seem insufficient. This is because each one usually focuses on just a single dimension of the problem. They do not explain the fact that when there is a female in the family she is (automatically) the potential caregiver and the one who is most likely to “obviously” and “naturally” assume this role. Nor do they provide any insight into those situations where women in fact refuse to assume this role or have only limited involvement in the provision of care.

A more comprehensive explanation can be found in general theories of gender that integrate these dimensions. Joan W. Scott (1986) understands gender as a constitutive element of social relationships based on perceived differences between the sexes that involves four elements: culturally available symbols and myths; normative concepts that set forth interpretations of the meanings of these symbols and demand certain types of action in response to them (and define such actions as the only ones that are obvious and correct); social institutions and organisations (family and kinship, the labour market, education and the polity); and subjective identity (socialisation, the acceptance or construction of a masculine or feminine identity). These four elements are always interrelated; no one of them operates in isolation from the others. When asking how elderly care is gendered we need to pay attention to all of them.

However, all these elements are shaped, confirmed and altered through social interactions. Judith Butler proposes understanding gender as performative – as a series of repeated acts that create the effect of the stability and substantiality of gender. The gendered subject is then constituted by these acts. Gender is a mandatory performance that takes place in the context of a regulatory network of penalties, sanctions and taboos, all of which must be adhered to if a person is to be intelligible to others and to qualify as a subject, or as “real.” The performance is neither conscious, nor voluntary nor external to the subject (Butler 1999: 25, 179, 190). Similarly, West and Zimmerman argue that gender should be viewed as something that is “accomplished” or that is continuously created and reconstructed through actions that conform to the expected behaviours of women and

men (West and Zimmerman 1987: 126). Gender is thus dynamic, it is something that “we think” and “we do” (Gherardi 1994). As such, it acquires meaning through the social practices that constitute it (Bruni et al. 2005). Care is a performance space in which gender is enacted; it represents one of the many domains in which the “doing” of gender occurs. It involves not just the caregivers but also those who receive care – both parties “do” gender through their interactions with each other, with other people and with the external institutions that are tied up with informal care.

Language and how it is used are the main instruments by which social actors perform gender and enact gender norms (Speer 2005). According to discursive psychology, self and identity (including gender identity) must be seen as “being accomplished in the course of social interactions; reconstructed from moment to moment within specific discursive and rhetorical contexts, and distributed across social contexts” (Edley 2001: 205). Women, when speaking about their experiences of providing care, use “culturally familiar and habitual lines of argument comprised from recognisable themes, common places, and tropes” (Edley 2001: 202) that may denote the provision of care as feminine or link femininity with providing care, and they thereby position themselves as “women.” Femininity must be conceptualised not as the cause or the reason why women take on the role of caregiver, but as a consequence of their assuming this role (Edley 2001: 192). In order to understand why care for the elderly is so associated with women and why women dominate in the caregiving role, it is necessary to examine how gender is “done” within a given culture, that is, what kind of self-representation and self-perception (in connection with caregiving) a particular culture endorses and promotes if a person is to be regarded as and feel like a “real woman” or a “real man,” or what positions people can take in the discourses and practices of care in order to produce and reproduce or transform their gender identities.

Concurrently, we need to recognise how care is situated in the wider system of the division of labour in society and social institutions and within the family and the labour market in particular, which means understanding what activities and positions are considered appropriate and desirable for women and for men and how these activities are socially recognised and validated. The external structures and institutions that influence the actions of women caregivers and their interactions with others

while they provide care are seen as simultaneously the causes and the consequences of the construction of gender. Although these structures are the product of human action, and are constantly being reproduced, reinforced and legitimised by these actions, once they are put in place they constrain people's actions and are perceived by people as external pressures or forces that they have no influence over (Bourdieu 2002). However, the existence of these structures is dependent on the perpetual repetition of them by subjects through their actions (Butler 1999). This opens the door to the transformation of categories and power relations, that is, for "undoing gender" (Risman 2009).

Methodology

In this study, I draw on a qualitative biographical study that focused on women caring for an elderly and dependent mother or, in some cases, caring for both parents. The study concentrated on middle-aged women (who, according to available data, are the people most likely to become caregivers; see Klímová Chaloupková 2013); my respondents were between the ages of 48 and 60 and the parents they cared for were aged 75 or over. Some of them were of pre-retirement age, while others were already retired. The research sample was selected to ensure that in one portion of cases (a total of 16), the elderly person who had received care was deceased, while in the other portion (13 cases) the women were still providing care at the time of the interview. In this way, it was possible to view the period of care as a life stage with a duration period and an end. The sample was created using the snowball method. First, respondents were recruited from among my acquaintances who then referred me to other people in their social networks. Special attention was paid to including women from diverse socio-economic backgrounds, education levels and family situations. The interviews were conducted in the capital of the Czech Republic (Prague), in mid-sized and small communities in its vicinity, and in two remote rural regions. The sample included several women who at some point had decided to cease providing care within the family and to transfer their mother or father to residential care. In the second phase, this sample was expanded to include a sample of eight men providing care. The interviews with the men are used in this paper where necessary to offer a contrast to the women's narratives

(to show how femininity is linked to care and care to femininity). A full analysis of the men's narratives is, however, presented elsewhere (Dudová & Vohlídalová 2018).

The analysis omits the narratives of the persons receiving care. Although gender is enacted in the interactions of both parties in the caring process, and the way care is received probably plays an important role in how the caregivers speak about and perform their caring role, I decided to focus on the discourses of caregivers only. The issue I am interested in is the production and reproduction of femininity in the narratives of caring women, as I believe that understanding how this occurs will help explain why women dominate in elderly care. In the interviews, the caregivers were given the opportunity to express their own position in the space of the discourse on care. They were given this opportunity in the specific situation of a face-to-face discussion with a researcher one generation younger than them (the author of this paper), who acknowledged at the beginning of the interview that she herself had the experience of helping her mother to care for her grandmother.

I used the biographical interviewing method (see Schutze 1980). The women were first allowed to freely narrate their life story, and in the second part of the interview they were presented with questions. The narrative interviews served as a space in which the respondents discursively constructed and created gender in front of or in cooperation with the interviewer. Over the course of their narratives, the interviewed women were essentially "re-doing gender" – both in the way they presented their decisions, actions and thoughts to the interviewer, and in the way they reinterpreted the events in their lives and what they felt others expected of them. The narratives were the medium through which they constituted their identity, including its gendered aspects, and reflected the cultural norms and expectations placed on them. The interviewer served as the audience before whom the respondent displayed and affirmed her gender identity and also served the respondent as a kind of arbiter assessing how much the narrator's actions and responses met the accountability standards of her gender category (West & Zimmerman 1987). The narratives were created in the interaction between the interviewer and the interviewee, and the interviewees responded to who the interviewer was. Some social categories were visible and more or less readily available to them – my/the interviewer's age, gender, race and class (the author being a white woman one generation younger than the

respondents and working in academia); others were deliberately made explicit in the introduction to the interview (I shared my personal experience caring for my grandmother). The interviewees had every reason to assume that the interviewer/I shared the same cultural stories about care and gender (see Miller & Glassner 2004: 127-131). Simultaneously, in the interviews the interviewees were conscious of responding to an audience, that audience being who they imagined would ultimately read the results of the research (in most cases they imagined the audience would be policy-makers and the academic community). In both cases, the ways the narrators did gender depended on the interactional situation and the gender assumptions that entered it.

The next step involved combining a "narrative analysis" with an "analysis of narratives" (Polkinghorne 1995). First, I focused on the timing and course of each individual story by creating "story maps" for each narrative. All the key data and the timing of events in the respondent's life were recorded in a story map, along with the respondent's interpretations of the events, to which I added my analytical comments. I then used the method of coding and creating categories that is used in grounded theory methodology (Charmaz 2006). After the first reading and line-by-line topical coding, I compared the interviews and the parts of a narrative within each individual interview. I paid special attention to contradictions and incongruencies occurring across the narratives and in the narratives, namely, those that emerged as the interview unfolded. Gradually, I linked the analysis of individual narratives and the system of categories to create a single interpretive frame – an "analytical narrative" (Charmaz 2003). The deviant cases, if they appeared in the course of the analytical work, were thoroughly examined and discussed in order to revise, broaden or confirm the patterns emerging from data analysis. The original analysis was conducted in Czech (the original language of the interviews and the native language of the author). The quotes selected for this article were translated into English by the author. While translating, an effort was made to present the data as faithfully and accurately as possible. It is necessary to acknowledge that the translation of the talk-in-interaction is not without problems. Together with the transcription, the translation of the interviews should be seen as a process of "double rendering," in which a layer of interpretation is added to the original data (Nikander 2008: 229). Czech and English come from different language groups and

have different structures, semantics and syntax. The accuracy and transparency of the data could be increased by including the original quotes. However, as the subject of this paper is not a detailed linguistically oriented conversation analysis, to include the original would make the text less clear and readable. The author will readily share the text of the quotes in the original Czech upon e-mail request.

The analysis involved searching for key passages where respondents explicitly or implicitly talk about gender or construct gender through their talk. I paid attention to their inter-subjective interactions and experiences, institutional barriers and sources, social values and strategies for coping with different situations in life. The transcripts of the interviews provided me with a rich collection of material with which to study how the women, in interaction with me, constituted themselves as gendered subjects in order to construct gender in such a way that it appears stable and solid; how they enacted and reproduced gendered norms concerning care and thus constructed their gendered identity. I was also able to make note of any breaches and inconsistencies where their construction of gender is revealed to be unstable and fragile.

At the same time, the interviews allowed me to study the social organisation and structures of elderly care. Bertaux (2003) asserts that narrated life stories obtained from sociological interviews are a unique tool with which to observe these structures. Once a sufficient number of them have been gathered to allow for a comparison of a particular context or issue, they begin to reveal the "lines of social forces," that is, the existing social structures that shape social and historical processes. When people tell their life stories they are describing "how they hit these invisible lines, how these lines prevented them from doing what they wanted to do or, on the contrary, provided them with unexpected resources" (Bertaux 2003: 40). Their actions then either reinforce these lines or try to undermine them, and this applies equally to doing gender (Risman 2009). In the narratives of the women caregivers I interviewed, I looked for the discursive elements (terms, metaphors and figures of speech) that they used to construct their feminine identities in relation to care, but I also sought to identify any discursive elements that weakened or undid gender when the women resisted the structures that they felt had been imposed on them.

First, I examine the ways how the interviewed women presented their caring roles, and I show that this narrative is part of a shared normative

“cultural story.” Then I focus on how women narratively re-created their gendered identities in the interview situation when they were talking about care. In the last part of the text, I study the ways in which identity is tied to social structures, which are simultaneously the causes and the consequences of how women perform femininity in care. I conclude that instead of just doing “gender,” women caregivers do “gendered age” in their practices and narratives of caregiving.

Taking on the Caregiver Role: “The Obvious Thing to Do”

In most cases, at the beginning of the interview, the respondents portrayed the decision to take on the role of primary carer and to care informally at home for a family member as having occurred “naturally.” They were either unable or unwilling to explain exactly why they had made the decision to assume this role. At the start of the narratives in particular, many of them claimed that they had never reflected or deliberated much on their decision to care for their mother or father.

It was clear to me that it would be forever, till she dies. That was perfectly clear to me, but I didn't dwell on it at all. ... I did whatever I had to do, and somehow I didn't give it any further thought. (Diana, age 63, working retiree – teacher)

...The idea of her going somewhere else or something, that was never for a moment considered. She was simply going to be at home. (Tamara, age 62, retired, previously a factory worker)

Out of the 29 respondents, 11 in the first minutes of their narrative used the word “samozr'ejme” – which is best translated as “self-evident” – to describe how it came about that they became the primary caregivers. A respondent named Jarmila said for her assuming the caregiving role was “normal.” Lenka used the term “natural,” and Tamara said that no other solution “came into consideration.” Others described the course of events that led to them becoming the primary caregivers as occurring without any questions being raised or other options considered. There were two exceptions: Věra decided to care for her mother, who was suffering from cognitive impairment, because she “was already retired” and so she thought she “will give it a try” (Věra, age 63, working senior – teaching assistant), but she felt uneasy because her mother considered

it “self-evident” that Věra would provide care, while Věra expected more appreciation from her. Those daughters who did not consider it “natural” that they should be the ones to provide care nevertheless were confronted with this expectation from others, that is, the mother who needed care. Another exception was Ana (age 55, nurse assistant), who stated that she deliberated for one month whether she would offer 24-hour care to her mother. However, she only began to deliberate over her decision when the care her mother required started to be very time-intensive and she had to leave her job in order to continue caregiving.

Further along, however, the narratives revealed that taking on the role of primary caregiver was not an entirely automatic and obvious decision. Viewpoints and considerations slowly came out in the narratives that pointed to factors that had entered into their decisions and events that had challenged the obviousness of the decision. Presenting the decision to provide care as obvious, self-evident and natural is part of the dominant “cultural story.” According to Miller and Glassner (2004), quoting Richardson (1990:24), participating in a culture includes also participating in the narratives of that culture. The interviewed women used familiar narrative constructs that were usually based on stereotypes and on their “stock of knowledge at hand” (Schutz 1962). According to this cultural story, caring for a dependent elderly parent is the duty of any adult child (daughter). The women were drawing on narratives that emerged out of the social worlds around them (from what they thought everybody thinks, from what was expected from them and from what I, as their interlocutor, probably knew and took for granted). Only later, when trust had been established (between the respondents and me/the interviewer), did the respondents feel they were able to depart from the cultural stories and speak about their own experiences and express their doubts.

Lucie initially presented the decision to care for her mother as the obvious choice: “The way I saw it, one day I would be caring for my mother.” She then said, however, that when her mother’s health deteriorated to the point where she required 24-hour care, she began to consider seeking institutional care for her mother. When her mother first began to require more care, Lucie was working in a factory and was not supposed to retire for another 13 months. The fact that she was not yet retired was for her a legitimate reason for her being unable to immediately begin caring for her mother.

And then my mother fell, she broke her hip and actually spent 13 months in the hospital, in the chronic care ward, she was transferred there several times from the surgery ward because I was still going to work at the time and there was no one to care for her. (Lucie, age 60, retired, previously a factory worker)

Her mother ought rightly to have remained in the chronic care ward for a maximum of 90 days (this is the time limit beyond which a patient must be relocated from a hospital to a long-term care facility); Lucie nevertheless managed to make an informal arrangement with the hospital to allow her mother to remain there longer until Lucie retired. Lucie said that she was unable to imagine what she would have done if she had had even longer to work before retiring; she would likely “have had to place my mother somewhere until I was able to be at home.” Later in the interview I learnt that even when she retired, Lucie initially considered placing her mother in institutional care. She ultimately made the decision to care for her at home herself when she found there was no space available in any residential social care facility:

After those 13 months, then it was up to us [Lucie and her husband] whether we would take her home or whether we'd have to place her somewhere. But there was no space, nothing immediately available at the time. So we took her home, but I was retired by then, so we looked after her at home. (Lucie, age 60, retired, previously a factory worker)

Most of the women at first described the decision to care personally for a family member as an obvious one, but later their narratives revealed this was not entirely the case. Talking about caregiving is also talking about gender: presenting their acceptance of the care obligation to the interviewer as an automatic and obvious decision can be seen as a discursive practice of doing gender. At the beginning of the interviews, face to face with an unknown middle-class female interviewer, the women opted for a normative cultural story, and drew on a general cultural repertoire (Cameron 2001: 174) that portrayed them as accepting of the norm that it is a daughter's duty to provide personal care, regardless of what doubts, plans, considerations or deliberations may have surrounded the actual decision. As the interviews unfolded, it became clear that the women considered what time and space they had in which to provide care, the option of placing the senior in an institution or the (un)acceptability of deciding not to take on the responsibility of care. Most of these factors were gendered.

Gender Identities and the Norms of Care

To explain why the respondents initially presented their decision to take on the role of primary caregiver as obvious and automatic, we shall consider subjective identities together with gendered norms. How did the women construct their feminine identity? What self-presentation and self-perception did they see as culturally endorsed and preferred? What kind of normative expectations have they encountered and shared? According to Deborah Cameron (2001: 174), when people talk about their identity or some aspect of it, they draw from a defined “range of culturally intelligible” ways in which to do so; to do otherwise, that is, to perform and construct their identity outside this “range of possibilities” would render them unintelligible to others. So when talking about their understanding of care, in order to be “intelligible to others” and at the very least to the interviewer, the women likewise had to choose from a limited range of gendered normative repertoires.

Social norms stem from the culture of care that exists in a given context (Pfau-Effinger 2005). According to Naldini et al. (2016), the Czech society is one that places great importance on intergenerational solidarity and family care, and one where women are more likely to build a “moral career” as caregivers. These two levels on which gender operates – subjective identities and gendered norms – were very much intertwined in the narratives, as gender identities are formed through the acceptance and performance (or refusal) of gendered norms, and the norms are constantly reproduced by the actions (and interactions) of individuals.

Although gender appears in the quantitative data to be the strongest predictor of participation in family care, the women caregivers did not themselves mention gender as the main reason as to why they had become the primary caregivers. The connection between femininity and care was so deeply embedded in their identities that they did not feel the need to draw attention to it. For the respondents, face to face with a female interviewer, there was an assumed gender understanding underlying the interview situation. The women could assume that I was “from the same place,” that I knew and took for granted the stereotypes and assumptions about femininity in care and thus there was no need to explain. Instead, they presented a list of other factors that had led them into care. The link between gendered norms, identities and care became obvious in how they

referred to what role their brothers played in providing care (or, in other cases, how they remained silent on this matter), in their notions about what the provision of intimate physical care involves and in how they described the care that they expected in the future from their children. The unquestioned connection between femininity and care was made especially evident by the way they spoke about their sons (or brothers) and daughters. They spoke in terms that alluded to generally shared social knowledge about what boys and girls are like and what they do: "They say that girls lean more to their parents than boys" (Veronika); "Because she's the daughter," (Kamila, explaining who will take care of her once she will need care and why); "You know guys, they don't know how to do it" (Petra, talking about getting help with caregiving from her brother).

Their future expectations of care were pinned almost exclusively on their daughters and they either never even considered their sons as future caregivers or explicitly excused them from having to provide care because of their gender. In this way, they reproduced the gendered norms of care in their education of the next generation:

I probably wouldn't even want to live to an age where someone had to care for me. Because it's different when it's a mother and a daughter. I'm a daughter. Now, I have sons, what can you expect from boys? There it'll be about how, say, your daughter-in-law relates to you. (Věra, age 63, working senior - teaching assistant)

Some women thought that their son or sons would be able to care for them in old age. The reason they gave was that their sons possessed certain traits considered by them as feminine:

Well, [laughter] you know, he's a boy. From a boy [you'd expect] that he'd put you somewhere or something. Definitely not, he'd care, but that's because he's more a compassionate kind of person. If he's down to his last coin and there's a collection, he'll give it to [the collection]. (Jarmila, age 72, working senior - factory worker)

Sylva's narrative serves as a good example on which to further analyse how gender was constructed in the interview situation. At the time of the interview, Sylva had been caring for both of her parents for several years. Her parents lived in a family home across the street from her and Sylva went to their home every day to help them. It was only later on in her narrative that Sylva mentioned that her brother was living with her parents,

but that he refused to participate in any substantial way in providing care. It was only when the interviewer asked her directly about other family members that she even mentioned her brother and his wife. The respondents' silence about their brothers (which was observed also in the case of Lucie, Tamara, Marie and Veronika) reveals what standards of accountability men are held to in the eyes of the respondents when it comes to providing care.

Sylva later reported that her brother was involved in caring for her mother, but she (unlike other interviewees) considered his contribution insufficient. Here, she deviated from the cultural story and challenged the popular stereotype of daughters as caregivers, only to embrace the story again in the next step when speaking about intimate care. She wanted her brother to be more involved in providing care, but she also claimed that she could not expect him, for instance, to change his mother's diaper. Sylva regarded intimate tasks as her work, and while she did not entirely exclude her brother from having a role to play in care, she excluded him as a man from having to provide intimate care:

But then I can't tell my brother to change my mother's diaper. I could, but I won't, that's nonsense. He can't even take our mother to the toilet and I don't even want that from him. (Sylva, age 57, employed - branch manager)

It emerged in her narrative, however, that she did expect this kind of care from her brother's wife. Ultimately, Sylva presented the limited involvement of her brother in caring for their mother as a shortcoming of her sister-in law. Sylva's narrative illustrates how gendered the provision of intimate care for an elderly person is. Care is one of the fields where gender intersects with embodiment. The greater the degree of explicit body work involved, the more the activity is gendered, regardless of whether we are referring to the constructions of masculinities or femininities (Morgan et al. 2005: 9). The dirty parts of care work in particular are viewed mainly as women's work, and the feelings of disgust this work tends to evoke are further tied up with our society's understanding of femininity and masculinity (Isaksen 2005: 123).

Intimate care was deemed by the respondents to be stressful for both the caregiver and the care recipient. The caregivers have to devote themselves very intensively to providing care and have to overcome their own

barriers of embarrassment or disgust. The care recipients may experience fear because of the extremely intimate nature of this care, and because they are being forced to recognise their dependence, loss of control and consequently the loss of their own identity.

My husband helped me to lift her up, but it was very difficult because she was still aware of everything and didn't want to accept her son-in-law touching her. And being there when I was washing her. (...). And I can tell you, not everyone has a stomach for this. So he would help me to lift her up or to turn her, but I did the rest myself. (Tamara, age 62, retired, previously a factory worker)

In this light, the majority of the interviewed women felt it right to limit as much as possible the number of persons involved in providing this type of care, preferably to just one person – the primary caregiver. They also presented themselves as experienced and resilient enough to be able to cope without difficulty with this type of care, which they claimed is “not for everyone.” This consequently meant that the primary caregiver became almost irreplaceable, especially once it became necessary to provide the most demanding type of care. This feeling of irreplaceability may explain the greater burden of care placed on women and the higher level of stress women experience in connection with care (Calasanti 2003).

The way the respondents spoke about caregiving in the interview situation (their choice of vocabulary and specific means of expression) and the main narrative line served them as the means by which they constructed their gender identity. Talking about care means also talking about gender, or talking gender into being. Being a woman involves appropriating certain behaviours in conversation (or in an interview in this case) that members of their society have ascribed with a gendered meaning (they are understood as “feminine”) and presenting themselves through these behaviours to others (see Cameron 2011). In the case of my interviewees, this involved presenting themselves as the “obvious” caregivers, and speaking about women as better suited to providing care than men. It also involved establishing a sense of intimacy and solidarity with me as the interviewer, which they did by sharing their emotions and describing at length the details of their everyday experiences. When speaking about intimate bodily care, they described in detail situations in which they had to overcome their reluctance to deal with the bodily manifestations of the care recipient.

The case of informal elderly care in the Czech Republic

I bought that foam like they have in hospitals, so when it happened, she stayed leaning on the bed, and I sprinkled her [with it], now it was flowing down like this, so we had this paper pulp, so[and] I used that to wipe it up... (Lucie, age 60, retired, previously a factory worker)

But that kind of help with washing and such, that was hard. Before I got used to the fact that they were my parents who... . You wash them, you see their bodies so dilapidated, it's not a pleasant feeling. I think that was probably the hardest thing for me. Now I don't care, but it really was not pleasant at first. (Diana, age 63, working retiree - teacher)

Some explicitly welcomed the interview as an opportunity to share and clarify their contradictory feelings. In contrast, all the men who were interviewed in the later phase of the research spoke in more general terms, avoiding any detailed description of specific tasks associated with bodily care (they simply spoke about "hygiene" or the "physiological needs" of their parents that had to be taken care of).

The majority of the women also spoke in detail about the relationships between their family members, and they articulated their feelings and concerns, their sadness, and their fear of losing a close relative or of failing to deal with a difficult situation. In contrast, the men were mostly neutral, avoiding personal comments or descriptions of their feelings, and using impersonal pronouns. Thus, they (both the men and the women) fulfilled gendered expectations about the "right" way to cope with and experience emotions.

And that, I can't think about that, because I feel terribly sorry about it². That, that's probably for me the worst thing that I go through. That concern that I have to do everything, from ... she doesn't even recognise anymore what slippers are, what a shirt is, what sweatpants are, so it's obvious then. That for me is the worst and sometimes I break out in tears and can't stop them and I say to myself: What are you blubbering about, don't be silly. And I can't stop it, I have to cry it all out of me. (Helga, age 62, retired, previously a factory worker)

That's what you say, you have to get through somehow, somehow manage it. Then the worst thing was that one has to be careful not to overstrain himself. Because I once

² Some parts of the text are underlined by the author in order to emphasise the main points in the analysis - the terms describing emotions, the personal and impersonal pronouns and nouns.

experienced this burnout syndrome, I know there should be no overdoing things, because then a person just won't have the energy. (Jindrich, male, age 51, employed, middle management)

Men and women shaped their narratives according to the different accountability standards considered to apply to masculinity or femininity. The women in the sample were much more often intent on providing, what they called, the "best possible care," while the men were focused more on providing "adequate care" (see Dudová & Vohlídalová 2018). Women chose a style of narrative that can be termed "apologetic." They used the space of the interview to evaluate themselves in their role as a daughter and care provider. In the course of the narrative they measured themselves against the (unspoken) norms of "proper" care, and they oftentimes tried to come to terms with how, by their own measure, they fell short of those standards. All the women who provided care for a longer period of time mentioned situations and circumstances in which they had lost patience with the person they were caring for and did not respond in the ideal manner, or when they had yielded to their exhaustion or made a decision that was not consistent with their image of themselves or with general expectations. In most cases, they expected the interviewer to reassure them that they were providing care in the "right" way, and in several cases they even directly asked for this reassurance.

As Miller and Glassner's approach to the interview analysis (2004) implies, the way people do gender depends on the interactional situation and especially on the gender assumptions that enter it. Face to face with a woman interviewer, women and men will do gender differently. The women interviewed assumed that I shared their positions and stereotypes about care and femininity and they invited me to participate actively in the process of co-constructing their self (Cameron 2011). They were asking for a reaction, and specifically for a valuation of their caregiving. By contrast, the men who were interviewed sought during the interview to (re)assert their masculinity, which could be perceived as being undermined by their involvement in care, and they did this by using narrative styles that are viewed in our culture as masculine.

Even (or especially) in situations when the practices of actual caregiving could be interpreted as "undoing gender" – for example, when the women refused to provide care at home and chose residential care for

their relatives, or in the cases where it was men providing their mothers with intimate care, the space of the interview was used in order to re-do gender. Again, in the interviews, while the men interviewed reinterpreted the care they provided as a managerial, instrumental task, used general and expert language, and portrayed themselves as efficient and rational actors, the women in their narratives questioned whether they were good enough as caregivers and expressed a wide range of emotions. These differences do not reflect “real” or “natural” differences between men and women, but they are a means by which gender is performed. They should be seen as more or less conscious strategies employed by the speakers in order to appear adequate and socially desirable actors in the context of gender-structured and normative social rules (Mills 2003).

The Social Structures of Care

Gender, however, doesn't operate solely on the level of interaction; it can also be understood as both the cause and the consequence of the social structures and institutions that influence caregivers' decisions and constrain their actions. While these structures are experienced by people as external to them, they can be conceptualised as the social and material consequences of the gender performance and the norms, sanctions and taboos associated with it.

The interviewed women stressed two “external” factors in their explanations of why they were the ones who had become the primary caregivers: their availability and their belief that there was no alternative. Their availability was determined by whether they were employed or were able to adjust their working hours to accommodate the need to provide care, and also by how free they were from, or were able to free themselves from, other care obligations. The story of Jana shows how being employed influences the decision to assume care and what consequences this decision may have.

Jana lived her entire life with her parents in their family home. She began caring for her ill mother shortly after the death of her father, who until then had provided some of the care for her mother. Jana was working in a low-level administrative job. Given that her wages were the household's primary income, she initially did not consider leaving work. Jana had a sister who took it for granted that Jana would assume responsibility

for caring for their parents since Jana had been living with her parents all her life and would inherit their home.

Her mother's health gradually deteriorated, and Jana tried to arrange care so that she could also continue working:

... Since I had my job too, I asked a neighbour and gave him the keys so that while I was away he could always go in and check things. It happened several times that she fell, and since her mobility was poor, one time she had a gash on her forehead and she was bleeding, she tripped over the heater. ... And then I also asked a woman from my street, and she used to come by and look after her when I wasn't there. (Jana, age 67, retired, previously an office clerk)

In the end she decided to take early retirement in order to care for her mother, but she had only been retired for three months when her mother's health deteriorated further. Jana was no longer able to cope with caring for her mother given her own health and her mother's weight. So she decided to place her in a long-term care institution.

For Jana, early retirement meant a loss of income from employment and a reduced pension, and, from her perspective, it was all ultimately for nothing. While at the time of the interview she regretted not having left work earlier, when it would still have been possible for her to care for her mother at home, it became apparent from her story that she could not financially afford to lose the income she had from her job or the reduction in her pension that retiring early entailed. Still, she interpreted the fact that she did not care for her mother herself as a failure, as her having failed as a daughter.

Eight of the women in the sample were already retired when the need to care for an elderly parent arose. They spoke of having reached retirement age as a key factor that had made the decision to assume the task of care much easier. And this was true even though half of them continued to work after retirement in part-time or temporary jobs. They claimed that these were jobs that they could easily leave or combine with care because the jobs tended to have more flexible or shorter working hours. Jana was the only one in the sample who had decided to retire before reaching the official retirement age in order to provide care. The official retirement age of the cohort of women in the research sample ranged between 55 and 61 years. For the other women, having reached retirement age was interpreted as the key precondition for making the decision to assume

responsibility for care; the need to work, by contrast, was regarded as legitimate justification to seek some other form of care, for instance, in the formal sector.

This contrasts with the experience of the men who identified themselves as primary caregivers. The men did not see their jobs as something that interfered with their care obligations; they all worked full-time and had no intention of stopping work in the near future. The women caregivers did not want to leave their jobs to provide care as well, but they felt the need to justify this decision to themselves and to explain this decision during the interview. They envisioned providing care in a post-retirement timeline and imagined that they would gradually then spend more of their time on care. The men interviewed never mentioned the possibility of leaving or taking a break from their jobs, nor did they consider retirement as a precondition for providing (more) care. They planned to make use of formal or home-care services to meet any increase in how much time the care recipient in their lives required care.

The interviews did not bring any clear-cut evidence of the effects of social class on how the women spoke about or practised elderly care and combined it with paid work. The research sample comprises women of all socio-economic and educational categories, including low-skilled factory workers, managers and university teachers. Their motivations sometimes differed. Lower-income women of pre-retirement age said that they needed the money and therefore looked for other ways to organise care without having to leave the labour market. Women with higher income were usually motivated to continue working by the nature of their job. Still, the factors that led to them becoming the primary caregivers or using formal services were similar. An analysis of ISSP 2012³ data (Klímová Chaloupková 2013) similarly indicated that education, used as a proxy of socio-economic status, had no impact on the decision to provide informal care in the Czech Republic. This can be explained by the lack of both public formal care services in the country (which influences how much less educated and lower-income women participate

3 The International Social Survey Programme (ISSP) – 2012 Module Family and Changing Gender Roles IV. In the Czech Republic, the sample consisted of 1804 respondents aged 18+, representative for the Czech population.

in informal caregiving) and private care services (which influence how much higher-educated and higher-income women end up taking on care responsibilities).

Jana's story further suggests that in the eyes of the respondents, full-time informal care was only possible if other members of the family were able at least indirectly help in the provision of care. When the female respondents received assistance, in most cases it was from their spouse. This assistance did not mean that the duties and tasks of care were actually shared between them. Oftentimes it was simply a matter of the spouse being present at home while the respondent was at work, or it was that the spouse was able to provide financial support. The importance of this spousal assistance and support became most apparent in the narratives of the women who did not have a spouse – who were either single, divorced or widowed. All the non-married women saw their jobs as essential for them because they had no spousal income to rely on or anyone to share their expenses with. Consequently, they felt it impossible to take on full-time care on their own. According to ISSP 2012 data (Klímová Chaloupková 2013), Czech women living with a partner are 70% more likely to be providing informal care than women without a partner.

The last external factor mentioned by the respondents when they were explaining as to why they became caregivers was whether or not any alternatives to informal care were available. The narratives illustrate how a daughter's decision to care for her mother at home was often also a consequence of having no satisfactory alternative solution in the form of formal care. As Lucie's story made it clear, the decision to provide care at home in many cases was preceded by a period spent searching for suitable care services or institutions, although the decision itself was presented at the start of the interview as an obvious and automatic choice that was based solely on the belief that it is the responsibility and duty of a daughter to care for her mother. If the possibility to use quality professional care had existed, many of the respondents would likely have decided otherwise.

Tamara – who at the beginning of the interview stated twice, "There was no question at all of putting her somewhere else. She was simply staying at home" – herself undermined the obviousness of her decision to provide care 20 minutes into the interview:

...I took it on not out of the feeling that I owe it to them, but with the feeling that I simply have to do it. As I'd obtained information about various care institutions and all that. And I don't know, some people feel [formal care] is good enough, but I wasn't satisfied with it. (Tamara, age 62, retired, previously a factory worker)

It can be assumed that if formal care services deemed of adequate quality by the respondents had been available and affordable, they would have been less likely to become primary caregivers themselves. According to Kotšadam (2011), the quality and diversity of the formal care services that are available have a positive effect on their use, and their quality and availability also influence the "ethics of care" in a given country (in the sense of culturally shared care values and practices; see Flores et al. 2009). This in turn may have an effect on the gender division of work in the household, as has been suggested in a study on childcare by Ellingsaeter and Gulbrandsen (2007).

The lack of any alternative, that is, the unavailability of quality and accessible formal care, the earlier age at which women retire and the traditional division of labour in the family are thus the factors that lead women more than men to take on the role of primary care for an ageing parent, despite the high level of labour market participation among the working-age population of women. Conversely, being in pre-retirement age and having no life partner to rely on for financial and practical support constituted sufficient and legitimate reasons for women not to personally provide care for their parents. Structural factors – the lack of formal services of care, the early retirement age of women and their understanding of retirement as a time when they will be providing informal care and the acceptance of dependence on a partner's income – must however be considered to be not only a cause but also a consequence of the way women perform femininity in care.

Conclusion: Elderly Care and Doing Gender (and Age)

Based on biographical interviews with Czech women caring for an elderly parent, I have described and analysed the ways in which women narratively presented their "decision" to assume the responsibility of providing care to an elderly parent. When reinterpreting this life experience and presenting it in a face-to-face interview with a researcher, the respondents described this decision as an obvious and natural choice. They situated their narratives in a "cultural story" told from the point of view of the normative order, which offered them a general gendered cultural repertoire

from which to draw. Only later, as the interviews unfolded and trust was established, did they depart from the narrative in which it is taken for granted that daughters provide care, and did they begin to modify their accounts. In a deeper perspective, it is clear that at the given time there were many alternative ways more or less available to them in which care could have been provided or in which the stories could have been told. The result, however, was that it was a daughter or a daughter-in-law who assumed the responsibility of care (at least for some period of time).

Gender is constantly shaped and confirmed through interactions with other people. Women “did gender” when they performed care activities and in the interactions associated with these activities, and in this way they were constantly re-constructing their femininity in conformity with the prevailing norms and expectations. An example is their acceptance of responsibility for the provision of care and the automatic excusal of brothers from any such responsibility. The provision of intimate care formed a separate chapter altogether: The women considered it inappropriate for a man to provide this form of care, in conformity with heterosexual taboos, and at the same time they placed the needs of their parents (consistent care from one person) before their own (the need for rest or to share care with another person).

The case of the Czech Republic, as a post-socialist country, provides an example of a country in which the economic transformation and re-familialisation processes under way since 1989 have had a big impact on gendered social structures. Consequently, it provides a good illustration of the consequences of connecting femininity and elderly care in circumstances where the provision of care has been de-institutionalised and the norm of public responsibility for providing elderly care has been eroded and where we have seen the emergence of “welfare markets.” The Czech Republic has a long history of there being large numbers of women in the workforce, but it also has a very traditional gender culture, little governmental support for informal and formal care, and a shortage of institutions providing formal care. Moreover, the official retirement age of women is low compared to other European countries and is currently still lower than the official retirement age for men. In their decision to provide care, women caregivers were influenced by existing institutions and structural arrangements: Given that they retired at a younger age, they

were more available to provide care. The lack of good-quality services offering formal care led them to take on the responsibilities themselves. Given the conservative division of labour in the family, the women coped with care needs on their own and did not expect any help in providing hands-on care from their partner or brothers. By accepting the effects of these institutions and structures, they reproduced social institutions and structures through their own actions. For example, they regarded retirement age as the moment at which they should assume the role of primary caregiver, even though in many cases they continued to have jobs. If there had been no need for them to provide care, many of them would have continued to work in the job that they had before retiring. Because of the care duties that they perceived as their own, however, they often chose flexible working hours and more precarious job conditions with lower wages.

The respondents “re-did gender” during the interviews in the way they reconstructed their story: at first they described care as a responsibility that they “obviously” and “automatically” took on, positioning themselves as “women” in the normative cultural narrative, even though their stories gradually revealed a number of turning points that call into question how obvious this decision was. They presented themselves as irreplaceable in the caregiving role and as the only ones in the family capable of providing care. They expressed regret if they felt that they had not lived up to the norm, that they had been unable to provide care long enough or that they had not done everything they felt they could have for their parents’ well-being. The different standards of accountability that women and men are held to were manifested in the different styles or discourses they used in the course of their narratives.

The use of different discursive styles was however also a result of the interactional situation of the interview – the interviewees responded to the visible categories of the interviewer, and gender was one of the most evident categories. The stories would have been told differently to a different interviewer, but this does not mean that the narratives do not give access to the social realities “out there.” As Miller and Glassner put it, they “come out of worlds that exist outside of the interview itself” (2004: 131). The narrative constructs that the interviewed women shared and presented to the interviewer provide insight into the stock of knowledge

and cultural understandings that the women drew on to make sense of their experiences to themselves and to others, and to “create and maintain meaningful worlds” (Dawson & Prus 1993: 166, in Miller & Glassner 2004: 129), including their gender identities.

The narratives illustrate how the different levels on which gender manifests itself and is done are intertwined. Subjective gendered identities are linked to the overall family and care culture that exists in a given country: if there is a strong bias towards intergenerational obligations and informal care and a traditional gender division of labour, women are more likely to accept the obligation to care as part of their identities. Culture is intertwined with policies and institutions and each one influences the other (see Naldini et al. 2016: 627; Pfau-Effinger 2004). When formal care services are not available or not affordable, women are left with very limited choices. Explicit familialist policies (such as paying family members cash to provide care) then push them even more into providing the care themselves, as doing so gives them an alternative source of income.

Nevertheless, there were points in the narratives where the women could be seen to be “undoing gender,” mainly when they presented “legitimate” reasons for not having to provide time-intensive care, such as not having reached the retirement age yet and still having paid work, not having a partner and being in need of one’s own income or being able to obtain good-quality professional care services for the person in need of care. The most notable of the latter grounds for not providing care was the need to continue working until they reached retirement age. The women considered it evident that until they reached retirement age they would have to find some other way of getting care for their parents if they needed all-day care, usually by turning to formal institutional care, or by getting help from other family members. The relatively low official retirement age for women currently has the effect of reinforcing the connection between women and informal care in the Czech Republic. We could argue that instead of “doing gender,” the women interviewed were “doing gendered age” (see Utrata 2011). The women accepted the assumptions about age, paid work and family status that oblige them to provide care for their elderly relatives once they reach the statutory retirement age, while the men did not face any such expectations. Informal elderly care thus serves as an example of age and gender intersectionality, by making visible how

gendered identities, norms concerning age and gender, and social structures hold women accountable for providing intergenerational support.

In the case of the Czech Republic, we observe how women do and undo gender at the intersection of contradictory expectations: a traditional gender division of labour and a familialist care regime/culture that strengthens the link between femininity and care on one side, and the high full-time labour force participation of women on the other. With the raising of the statutory retirement age and the prolonging of working lives, doing “gendered age” (providing full-time informal care after retirement) may lead to a decrease in the availability of women to provide care.

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Men and older persons also care, but how much? Assessing amounts of caregiving in Spain and Sweden

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Abstract

We estimate how much caregiving men and women respectively do, and how much of the caregiving is done by older (65+) and younger persons, inside their household and for other households, in Spain and in Sweden. To assess this, we use self-reported hours of caregiving from two national surveys about caregiving, performed in 2014 (Spain, $N = 2003$; Sweden, $N = 1193$). Spain and Sweden have dissimilar household structures, and different social services for older (65+) persons. Caregivers, on average, provide many more hours of care in Spain than in Sweden. Women provide about 58% of all hours of caregiving, in Spain in all age groups, in Sweden only among younger caregivers. The reason is the dominance of partner caregivers among older Swedes, with older men and women providing equal hours of care. Family caregiving inside the household is

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more extensive in the more complex Spanish households than in Swedish households. Family care between households prevails in Sweden, where the large majority of older persons live with a partner only, or alone. This is increasingly common in Spain, although it remains at a lower level. We estimate that older persons provide between 22% and 33% of all hours of caregiving in Spain, and between 41% and 49% in Sweden. Patterns of caregiving appear to be determined mainly by demography and household structure.

Keywords: caregivers, family care, gender, household, partner, Spain, Sweden.

Introduction

Family care is receiving increased attention in many countries due to inadequate public resources and demographic challenges such as an ageing population, increasing childlessness and older people increasingly living alone in many countries (OECD 2013, 2017; Schulz & Eden 2016). By “family care”, we here refer to caregiving by family and other kin, neighbours and others, often called “informal care.” We exclude paid private care and public services such as Home Help.

A recurrent finding in population studies of family care is the dominance of female and younger caregivers, corresponding to the common notion that caregiving is primarily carried out by middle-aged persons, mostly women. Older persons (henceforth 65+) are generally perceived as receivers of care, although surveys in the Nordic countries usually find rather small gender and age differences in the prevalence of caregiving. In a recent Swedish government survey, 22% of adult men and 25% of adult women reported being caregivers, with the highest rates among 45- to 64-year-old persons (29%) and 65- to 80-year-old persons (26%) (National Board of Health and Welfare 2012). Spain is a contrast, with a great surplus of female caregivers in all age groups (Abellán et al. 2017a). A less publicised finding is the fact that for Britain, the United States, Sweden and Spain, there are about an equal number of male and female (older) caregivers for partners when they live just with each other (Askham et al. 1992, with personal communication, courtesy Emily Grundy; AARP 2014; Abellán et al. 2017b). In fact, a Swedish population

study of persons aged 75 years or more even found more older men than women caring for their partner, but mentioned this only in passing (Kristensson Ekwall 2004). A recent study more boldly announced that “Men do care!” (Wallroth 2016).

Living with just one’s partner is increasingly common among middle-aged and older persons in Western countries. Solitary living is also becoming more common, the shrinking remainder are various kinds of complex households (Iacovou & Skew 2011). Spanish and Swedish studies report that most caregivers provide rather few hours but also that the less numerous persons – who are often older themselves – who care for someone in their own household often provide many hours (e.g. CIS 2014 below; NBHW 2012). This boils down to whether the prevalence of caregiving corresponds to the amount of care – henceforth the number of hours – that is provided. To assess amounts of care is difficult at best, and the amount does not always imply how critical it is. The amount of care is often assessed by questions about how many hours per day/week/month the caregiver provides. A systematic review of questionnaires used to capture amounts of caregiving shows how complex the issue is (Cès et al. 2017).

Notwithstanding these difficulties, we will attempt to estimate amounts of caregiving in Spain and Sweden. Both countries have rapidly ageing populations, the age group 65+ make up 19%–20% of the population but have different long-term care policies and distinctly different household structures (Abellán et al. 2017a). Spain spends less than 1% of its gross domestic product (GDP) on public services for older persons, Sweden about 3% of its GDP (OECD 2013, 2017; Rodrigues et al. 2012). Yet, Spain is the only Southern European country that has rather high coverage rates of public, or publicly financed, services for older persons, a fact not widely known. For example, 4% of the 65+ are institutionalised, the same rate as in Sweden, and 6% use (publicly financed) Home Help, lower than Sweden’s 10% (2016 for Sweden, www.socialstyrelsen.se; Envejecimiento en Red 2017; IMSERSO 2017). Spain also has a vast supply of private home care workers, and residential care is often privately paid for by users or their families. Both countries have extensive alarm systems for older persons, and Spain has a good supply of day care, which is rare in Sweden. Spanish services have been expanding, while the Swedish

services have contracted (Ulmanen & Szebehely 2015). In Sweden, living alone has decreased among older persons (about 40% in the 1980s, and 32% in 2016) and about 60% live with just their partner (Sundström 2018). In Spain, 23% of older persons live alone, a rate that is rising, and 41% live with just their partner (Abellán et al. 2017a). All these factors are likely to affect patterns of caregiving in general and also the amounts of care inside households and between households.

Data and Methods

Our objective is to assess the amounts of care men and women provide in different age groups, inside and between households in Spain and Sweden, and whether these amounts follow the same pattern as the distribution of caregivers. To do this, we use one Spanish and one Swedish survey that obtained information about hours of caregiving. The Spanish main source was a survey carried out by Simple Lógica for the Unión Democrática de Pensionistas (UDP) in 2014 ($N = 2003$ for 16+, $N = 414$ for 65+). For Sweden, we used the Ersta Sköndal University College survey for their Civil Society project (ESUC), also performed in 2014 ($N = 1193$ for 18+, $N = 385$ for 65+).

Both surveys are national population samples of about the same size and with reasonably similar definitions of caregiving. In the Spanish UDP survey, subjects were asked if they cared for another person due to his/her illness or disability, helping with tasks of daily living. Caregivers for persons outside the subject's household were asked about how many hours of care they gave. Persons caring for someone in their own household were categorised as providing 24-hour round-the-clock caregiving in the original survey. We have censored this to 12 hours/day, which was the average for caregiving inside one's own household in the very large 2008 EDAD survey (Survey on Disability, Personal Autonomy and Dependency, see Oliva-Moreno et al. 2015; Abellán et al. 2017b) and also in another Spanish survey in 2014 (CIS 2014, below). In the Swedish ESUC survey, subjects were asked if they gave care to someone, inside or outside their household, with "special needs of care" due to old age, illness or disability, followed by a question about how many hours per month this amounted to. In ESUC, we maximised the number of hours to

12 hours/day, only 2% of all caregivers reported providing more hours of caregiving than that. In the UDP survey, 2% of all caregivers for someone in another household reported providing more than 12 hours of care per day. In ESUC, with this restriction, caregivers aged 18–64 years provided on average 68 hours of care per month for someone outside their household, and 49 hours/month for someone in their household. Among older caregivers, the average amounts were higher: 77 hours and 154 hours, respectively. When they cared for a partner in their own household they provided, on average, 5 hours of care per day.

For an overview (Table 2), we use three other sources to assess how stable our findings are: for Spain the 2008 EDAD survey (Abellán et al. 2017b) and a Centro de Investigaciones Sociológicas survey in 2014 (CIS, study number 3009, 2014, $N = 2472$ for 18+, for 65+ $N = 578$), and for Sweden a 2012 government survey (NBHW 2012, $N = 8202$ 18+, for 65+ $N = 2719$). All of these were representative population surveys. We used the chi-square test of independence for variables in the cross-tabulations, and we also calculated a z-score test to assess differences in population proportions (percentages) between Spain and Sweden. For all tests, the significance level was set at 5%. As mentioned, the UDP survey by default fixed caregiving inside one's household at 24 hours/day. If we had used that amount it would have doubled the amounts for these caregivers, but with only marginal effects on gender shares. Men's share would rise 1 percentage point, and older caregivers' share would rise 2 percentage points. The proportion of care given within the household would rise but with no change by gender. Our transformation of care given inside one's own household to the average of 12 hours/day therefore seems reasonable. As mentioned, averages for caregiving inside one's own household were about 5 hours/day in Sweden.

Results

Table 1 describes how common caregiving is among younger and older men and women. In both Spain and Sweden, women are more likely than men to be caregivers among younger persons, and the gender difference among older persons is negligible. The independence test suggests that gender is unrelated to caregivers' age; men and women care regardless

Table 1. Percentage of the population who define themselves as caregivers, by gender and age group, Spain and Sweden, 2014

Age	SPAIN			SWEDEN		
	Men	Women	Total	Men	Women	Total
<65	14	19	16	14	20	17
65+	14	13	14	20	21	21
Total	14	18	16	16	20	19

Chi-square test of independence, sample size: Spain ($p = 0.722$), Sweden ($p = 0.342$).

Sources: Our own computations on the UDP and ESUC surveys.

of age. Therefore, the differences in percentages between Spain and Sweden are significant in Tables 1, 4 and 5, except for younger men in Table 1.

In Table 2, we use three different Spanish and two different Swedish surveys to assess the stability of caregiving patterns. The various surveys all indicate that quite a large, but varying, proportion of caregivers are older themselves and also provide large amounts of all care. In Spain, older caregivers provide between 22% and 33% of all hours of informal care, while in Sweden they provide between 41% and 49%. Spain (still) has many younger caregivers; however, most of the caregivers are in their late forties or near retirement age in both countries.

The frequency of caregiving in different age groups is consistently higher in Sweden. Variations in caregiving prevalence in one case (Instituto Nacional de Estadística 2008) are due to a quite narrow definition of caregiving (being the main caregiver), while in the rest they are probably due to random variations between different surveys.

The average number of hours of caregiving by younger and older male and female caregivers is described in Table 3.

There are both differences and similarities between younger and older Spanish and Swedish male and female caregivers. In both countries, older caregivers tend to provide more hours of care. On average, Spanish caregivers report two to four times more hours of caregiving than their Swedish counterparts.

Table 2. Proportion of older persons among all caregivers, and in all hours of caregiving, Spain and Sweden, selected years

	SPAIN			SWEDEN	
	EDAD	CIS	UDP	NBHW	ESUC
	2008	2014	2014	2012	2014
% of all carers	33*	20	18	32	37
% of all hours	31	33	22**	41	49**

*Percentage of persons designated as main caregivers.

**Using 12 hours/day: In the very large EDAD 2008 survey, this was the average number of hours provided by persons caring for someone in the same household. The UDP survey by default set the amount at 24 hours/day for caregivers living with the cared for person. In the Swedish ESUC, we censored reports similarly, maximising reports at 360 hours/month.

Sources: Spain: INE: Survey on Disability, Personal Autonomy and Dependency, 2008 (EDAD); CIS: Survey on Care for Dependents, 2014; UDP: Survey on Caregiving, 2014. Sweden: The National Board of Health and Welfare, 2012 (NBHW); Ersta Sköndal University College Survey, 2014 (ESUC).

Table 3. Hours of caregiving among caregivers, by gender and age group, Spain and Sweden, 2014

Age	SPAIN			SWEDEN		
	Hours/day			Hours/day		
	Men	Women	Total	Men	Women	Total
<65	7	7	7	2	2	2
65+	9	10	9	4	3	3
Total	8	8	8	3	3	3

Sources: Our own computations on the UDP and ESUC surveys, using the restriction on reported hours described in the footnote of Table 2. Statistical means.

Table 4. Proportion of all hours of caregiving, and proportion of all caregivers, by gender and age group, Spain and Sweden, 2014
Per cent

Proportion of all hours of care						
Age	SPAIN			SWEDEN		
	Men	Women	Total	Men	Women	Total
<65	33	45	78	19	34	51
65+	9	13	22	26	23	49
Total	42	58	100	44	57	100

Chi-square test of independence: Spain ($p = 0.907$), Sweden ($p = 0.076$).

Proportion of all caregivers						
Age	SPAIN			SWEDEN		
	Men	Women	Total	Men	Women	Total
<65	35	47	82	26	37	63
65+	8	10	18	18	19	37
Total	43	57	100	43	57	100

Chi-square test of independence: Spain ($p = 0.918$), Sweden ($p = 0.523$).

Sources: Our own computations on the UDP and ESUC surveys, using the restriction on reported hours described in the footnote of Table 2.

Female caregivers in Spain and Sweden provide more hours of care, with the exception of older Swedish male caregivers who report more hours of care than older female caregivers.

This is also visible in the proportion of all care that men and women give, as shown in Table 4, which also gives the corresponding distribution of caregivers. There is no interaction between the gender and age of caregivers, and both variables are statistically independent.

Overall, there is equal overrepresentation of female caregivers in both countries among primarily younger persons (under 65), and women in general in both countries provide more hours of care. Female caregivers in Spain provide more hours in all age groups, while in Sweden this is

Table 5. Distribution of all hours of caregiving, inside and outside, respectively, of one's household, Spain and Sweden, 2014
Per cent

	SPAIN			SWEDEN		
	Men	Women	Total	Men	Women	Total
Inside	33	43	76	17	18	33
Outside	9	15	24	28	39	67
Total	42	58	100	44	57	100

Chi-square test of independence: Spain ($p = 0.608$), Sweden ($p = 0.074$).

Sources: Our own computations on the UDP and ESUC surveys, using the restriction on reported hours described in the footnote of Table 2.

only true among younger caregivers. Amounts of caregiving – hours of caregiving – tend to follow the distribution of caregivers in Spain, but somewhat less so in Sweden. The reason is the large proportion of partner caregivers among older Swedes.

In Spain, most (three-quarters of all hours) care is provided inside one's own household, especially among male caregivers, as shown in Table 5.

Younger caregivers (under 65 years) in both countries provide the largest proportion of all care to persons in other households, while in Spain they provide 89% of all hours of care to persons "outside" (and 75% of all "inside" care; calculations available on request). In Sweden, most (two-thirds of all hours) caregiving is between separate households. The exception is older male and female caregivers, who provide equal amounts of care "inside" and "outside." Caregiving inside one's household or to persons in other households is unrelated to the gender of the caregiver, according to the independence test.

Discussion

There is a higher proportion of older caregivers in Sweden than in Spain. It is therefore not surprising that older Swedish caregivers also contribute a larger share of the total amount of caregiving than older caregivers do in

Spain's more complex household structure. Yet, Spanish households are changing, with older Spaniards increasingly living just with their partner or alone (Abellán et al. 2017a, 2017b).

In Spain, most (three-quarters) of the hours of family care are provided inside the caregiver's household, while in Sweden most (two-thirds) of the hours of family care are provided between separate households. The exception is older male and female Swedish caregivers, who provide equal amounts of care inside and outside their own household. This is expected, as younger Swedish caregivers often provide care to parents and others living elsewhere, while older caregivers often provide care for a partner, and frequently for many hours. Our analyses suggest that older persons provide 2 to 3 hours out of 10 hours of informal care given in Spain, and about double in Sweden. Generally speaking, partnered persons provide more care, inside and outside their own household, than persons who live alone (calculations not shown here). The latter probably have fewer potential receivers and may also suffer disabilities due to their, on average, higher age.

Spanish caregivers on average provide many more hours of care than Swedish caregivers, probably due to the more complex Spanish household structure, higher disability rates of older Spaniards and less available public services. For example, a third of Spanish older people still live in various complex households, which is very unusual in Sweden (Abellán et al. 2017b). Disability rates are about double among older Spaniards compared to older Swedes (OECD 2013). More extensive Home Help services in Sweden than in Spain may influence informal caregiving, as there can be a certain "trade-off" between informal and formal care (Jiménez-Martín & Vilaplana-Prieto 2012). This should mostly affect caregiving to persons in other households, as Home Help services primarily target persons who live alone. Public Home Help services provide few hours of care in both Spain and Sweden, suggesting marginal effects on the patterns we have seen. Nevertheless, support provided under the Spanish Dependency Law introduced in 2007, which reimbursed caregivers, might have contributed to more caregiving inside the caregiver's household up to 2012 when, due to the economic crisis, some benefits were cut.

As mentioned, Spain spends a much smaller proportion of its GDP on public services for older persons than Sweden (Rodrigues et al. 2012;

OECD 2013, 2017). The difference is probably due to higher co-payments, use of migrant care workers and other private, out-of-pocket paid services in Spain. The economic crisis in Spain (2008 and after) has checked the development of social services; therefore, more care and associated costs have remained with or returned to the family.

A limitation of our study is that amounts of caregiving – whether measured as hours of providing care or otherwise – are notoriously difficult to assess, which is visible in the spread between the different surveys. One reason is that the boundary between socialising and caregiving is opaque. Some studies include socialising and “monitoring” in caregiving and in two major Swedish surveys, seven out of ten caregivers provide “social company, stimulation and entertainment,” which is the single most common support that is provided (Busch Zetterberg 1996; NBHW 2012). When the giver and receiver of care share a household, caregiving becomes even more opaque than in the case of inter-household support (Cès et al. 2017). A Swedish study which compared caregivers’ recalled time use and their time diaries found that most caregivers underestimated the amounts of time they gave. This was particularly true for older and female caregivers (Flyckt et al. 2011). A person with dementia or severe disability may need help or monitoring-supervision 24 hours a day (Wimo & Nordberg 2006). As mentioned, we use the average of 12 hours/day for caregiving inside one’s household in the Spanish UDP survey, as this appears to be a reasonable approximation of the amount of care provided. It is also conservative; use of the original default amount of 24 hours in the survey would have emphasised older caregivers even more.

Our cross-sectional data cannot disclose how much care is provided over the life course. Caregiving accumulates over time and therefore is more common over a longer period than in a cross-sectional study, as shown in a study from the United States (Butrica & Karamcheva 2014), but we do not know of any study that has recorded how much time caregivers have spent altogether in these longer (or repeated) commitments. Perhaps this is unknowable.

With all these limitations, older persons emerge as important family caregivers. We also find that men are caregivers more often than commonly thought, both with regard to how often they give care, and how much care they provide. This is particularly the case among older Swedes, where men perform at least as many hours of caregiving as women,

mostly caring for their partner. This supports an early study by Chappell which found gender differences in caregiving, but these gender differences vanished in cases of severe needs of the partner (1989).

Another intriguing issue is the *content* of the care given. Men and women may be doing different things; for example when a son and a daughter-in-law help an elderly person, the man may be doing house repairs (not always recorded in surveys about caregiving), while the woman may be performing personal care, cleaning and other house work. Both “male” and “female” tasks can be essential for keeping the recipient in her/his home, but at least some men also perform traditionally “female” tasks. It is sometimes noticed that men receive more praise for their helping and caregiving than do women (Milne & Hatzidimitriadou 2000). This may be due to the fact that male caregiving in general has been overlooked. An early study analysed the division of labour between wife and husband when caring for older relatives and suggested that the role of husbands had been neglected (Litwak & Kail 1980).

The importance of older caregivers, for partners and others, seems to be an effect of older persons being increasingly of better health, and more often living with a partner, illustrated by an avalanche of golden weddings in Sweden (Lennartsson et al. 2017). These demographic factors appear to explain the important role of men and older persons in general in the Swedish panorama of caregiving. They are somewhat less important in Spain, but are probably increasing. The often overlooked significance of older caregivers in general and of (older) male caregivers suggests a future convergence in patterns of care.

Future caregiving may also depend on factors such as postponed disability, family size, household type, technological changes, home improvements and cultural norms. As mentioned, there are also indications of cutbacks in Swedish social services, which may affect caregiving (Ullmanen & Szebehely 2015). Yet, demographic changes, especially the increasing joint survival of older men and women who live just with each other, may be the intrinsic factors in the patterns we have described. When men increase their caregiving, gender inequalities may diminish (Larañaga et al. 2008) and potential consequences of caregiving – negative and positive – may affect men as often as women.

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Dementia in a regional hospital setting: contextual challenges and barriers to effective care

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Abstract

Dementia is a growing public health problem, which may be under-recognised and poorly managed in regional hospitals. With projections of increasing dementia among older adults in regional and rural areas, knowledge about dementia and capacity of professionals to provide best-evidence care is paramount. This research investigates the challenges of dementia care in a publicly funded regional hospital in Australia. The study elucidates prevalence of dementia-related admissions, costs of treatment, length of stay and capacity for dementia care. A mixed methodology was employed in this study, including analysis of hospital records ($N = 2405$), dementia knowledge surveys ($n = 50$) and semi-structured interviews with clinical staff ($n = 13$). Hospital records showed that dementia-related admissions were lower than population prevalence reported in regional Australia. Dementia patients, however, attracted significantly higher treatment costs and greater length of stay than age-matched admissions who did not have a diagnosis of dementia.

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Clinicians reported several obstacles to effective dementia care, including staff knowledge deficits, environmental challenges, resource constraints and organisational factors.

Keywords: dementia, barriers, care quality, regional hospital.

Introduction

Dementia is the second leading cause of death among older Australians (Australian Bureau of Statistics 2015) and has been identified as an emerging global health and human rights priority (World Health Organization 2012) and an imperative for policy action (Organisation for Economic Cooperation and Development 2015). With no cure for common forms of the syndrome and a progressive trajectory of decline (Kurrle et al. 2012; Mitchell et al. 2009), the impact of this condition on the hospital sector is significant and costs to the health system are increasing (Australian Institute of Health and Welfare 2012). Dementia is commonly understood as a slow deterioration of cognitive faculties; however, the underlying pathology can prompt the emergence or exacerbation of acute concerns such as pneumonia, falls, urinary tract infections, medication overdoses, as well as behavioural and psychological symptoms (BPSD), including an impeded capacity to report pain (Kurrle et al. 2012; Takai et al. 2014). In many cases, dementia-related complications result in an unplanned visit to the emergency department and hospitalisation (Sampson et al. 2013). It has been reported that the distress and disorientation of acute hospital admission can exacerbate the effects of dementia as a result of unfamiliar environments, people and routines (Houghton et al. 2016). When admitted to hospital, people with dementia experience adverse outcomes at higher rates than individuals who do not have dementia, including increased mortality, unnecessary interventions, increased complications and higher rates of readmission (Alzheimer's Australia 2014). In the context of this research, an admission is a hospital visit requiring a stay of one night or more resulting from a pre-planned treatment or an emergency department visit.

Australian Government modelling forecasts the prevalence of dementia will triple within the next three decades to reach 900,000 diagnosed cases by 2050 (Australian Institute of Health and Welfare 2012).

Currently, dementia care attracts an annual expenditure of over 2 billion Australian dollars per year, with hospital-based care accounting for approximately 150 million dollars (Australian Institute of Health and Welfare 2012). Contemporaneously, dementia is known to be underdiagnosed within Australia and other developed countries (Connolly et al. 2011). With rising prevalence of dementia and increasing demand for acute sector services, regional hospitals (acute-care facilities outside the service area of larger metropolitan centres) are likely to be particularly affected. Issues that predispose regional areas to disproportionate impacts from dementia include rapid population ageing associated with outmigration of younger adults, growing preferences for “ageing in place” (remaining in familiar homes and communities) among the very old, higher rates of risk factors for dementia (such as obesity, smoking and high blood pressure) and limited access to diagnostic and treatment services (Alzheimer’s Australia 2007; Davis & Bartlett 2008).

Systematic reviews have identified that dementia care research focusses predominantly on the residential and primary care settings, with comparatively little consideration of acute care (Houghton et al. 2016; Moyle et al. 2008). The availability of skilled staff has been identified as one of the key barriers to the provision of appropriate, person-centred dementia care in the acute care environment (Bail et al. 2013; Moyle et al. 2008). Regional hospitals, in particular, play a key role in delivery of health-care and face many challenges, including resource constraints and staff retention (Buykx et al. 2010). Continuing education has been identified as a potentially useful approach to improving capacity for care and patient outcomes in hospital settings, particularly where resources and expertise are otherwise limited (Bloom 2005; Forsetlund et al. 2009).

Despite challenges to effective dementia care, few studies have been conducted to assess the dementia education and training needs of regional hospital staff, although some research suggests clinicians in these hospitals may be underprepared and under resourced for coping with patients who have complex cognitive conditions (Ellis & Philip 2010).

Research Aim

This research addresses the existing gap in information about dementia care in regional hospitals and informs the development of hospital-based

dementia education interventions. Specifically, this research investigates the prevalence of dementia in a large publicly funded regional hospital, costs of care and length of stay, staff knowledge of the condition and the capacity for effective care and treatment.

Methods

Setting and Participants

A large publicly funded regional hospital in Tasmania, southern Australia, was selected as the sampling frame for this study. Tasmania is an appropriate location for this study due to its high proportion of older adults in relation to other Australian states and territories, high rates of health risk factors for dementia and its regional setting, which contributes to poorer access to health services (Davis & Bartlett 2008; Jackson 2002, 2007). The regional hospital that formed the sampling frame for this study is typical of facilities outside the major metropolitan areas in Australia. It provides emergency care and specialist surgical treatment, is moderately sized with 501 patient beds, provides a central hub for surrounding rural townships and serves as a training centre for medical interns. Participants included clinical staff members who were employed at the hospital during the winter of 2015. Clinical staff refer to all currently employed health professionals with a 3-year degree or higher in their specialised field. This cohort included doctors, specialists (including geriatricians), nurses, hospital interns (senior medical students), physiotherapists and other health professionals. Winter was selected as the most appropriate time frame for the analysis of admissions data as this is the period when the largest numbers of older adults are admitted to hospital for a stay of one night or more (Walker et al. 2016).

Design

The research was designed as a mixed methods study. Methods of investigation included (1) analysis of de-identified hospital records; (2) administration of the Dementia Knowledge Assessment Scale (DKAS) among clinical staff (Annear et al. 2015); (3) administration of demographic questions; and (4) analysis of transcripts from semi-structured interviews.

De-identified patient records of hospital admissions were collected to establish the prevalence of dementia-related admissions (categorised in admission records as *dementia* or *dementia with delirium*) and calculate costs of treatment and length of stay among admissions during a 3-month winter period. The primary quantitative outcome measure was knowledge of dementia recorded on the valid and reliable DKAS (Annear et al. 2015). The DKAS measures understanding of causes and characteristics, risk factors, communication and engagement, and care needs related to dementia. It contains 27 items that are rated on a 5-point Likert-type scale, which ask respondents to assess the veracity of statements about dementia that are verifiably true or false. Each item is scored out of 2 points (for a total score of 54) with a full mark awarded for correctly identifying the veracity of a statement, a half mark (1 point) awarded for an expression of uncertainty (probably true or probably false) and no marks for an incorrect response or an "I don't know" answer. The DKAS has demonstrated good reliability ($\alpha = 0.89$) and validity and has previously been administered and pilot tested with large international populations (Annear et al. 2015). The DKAS has been validated for use with diverse populations of health professionals in Australia and Japan and has undergone confirmatory factor analysis (CFA) with large samples (Annear et al. 2017) and tests of concurrent validity (comparative analysis with the Alzheimer's Disease Knowledge Scale) (Annear et al. 2016). Semi-structured interviews focussed on four areas: (1) the prevalence and challenge of dementia-related admissions; (2) perceived capacity for management of people with dementia; (3) the experience of treating people with dementia in the regional hospital environment; and (4) organisational influences on dementia management. Data collection occurred after the study was reviewed and approved by a University Human Research Ethics Committee (Reference Number: H0014084).

Procedures

As described earlier, a mixed methods design was used to explore the dementia care capacity of the regional hospital due to the multi-faceted nature of the research problem. All currently employed clinical staff ($N = 150$) were approached via email and invited to participate in the study during September 2015. In addition to hospital staff participants, de-identified

hospital records ($N = 2405$) for adults aged 55 years and older (including younger onset dementia that often has a more complicated trajectory and symptomatology) who attended the hospital in winter (June to August) 2015 were reviewed to assess dementia prevalence, costs of care and length of stay. An age of admission of 55 years (and older) was used to account for individuals who may have younger onset dementia. This is important as the initial pathology of dementia can begin decades before death in the common forms of dementia (including Alzheimer's Disease and Vascular Dementia). Staff interested in participating followed a web link from an invitation email to an information page about the study and then completed an online version of the DKAS (Annear et al. 2015) and demographic questionnaire. At the end of the questionnaire, respondents indicated their willingness to participate in a further 30-minute interview. Staff who consented to further research participation were then invited to attend a semi-structured interview with the lead researcher, which was recorded and transcribed to generate qualitative project data.

Data Analysis

Descriptive statistics (including means and percentages) were used to describe the sample and report diagnosed dementia prevalence and staff dementia knowledge scores. Dementia prevalence information was ascertained by assessing primary admissions, nursing notes and electronic health histories. All patient records for individuals aged 55 years and older for the 3-month winter season in the year prior to the analysis were included in the study, with no patient records excluded. The records represent the full admissions, treatment and discharge history of an anonymised group of middle-aged and older patients. Treatment cost and length of stay information were calculated by linking individual diagnostic codes from patient records with national average costs (cost of treatment estimates provided by the Australian Government) and assessing patient records to identify admissions of individuals who had a diagnosis of dementia. Mann-Whitney U tests were employed to compare treatment and length of stay information. Spearman correlations were employed to assess potential associations between cost of treatment age and death during hospitalisation. SPSS (version 20) was used when conducting statistical analyses (IBM Corp. 2011).

A two-step coding procedure, employing NVIVO software (QSR International 2012), was used to analyse qualitative interview data (Charmaz 2014; Lofland & Lofland 1995). To enhance rigour in the qualitative analysis, transcribed data were coded independently by two researchers and inter-coder reliability was calculated. The first step involved a review of transcripts for categorical statements relating to barriers to effective dementia care. Following this, analytical coding was conducted to identify respondent statements that best reflected underlying themes. The second step involved the comparison of analytic coding (coding that aimed to draw out the latent or underlying meanings in interview data) across two researchers and the development of a thematic description for the commonly identified analytic codes (one overarching theme and five sub-themes). Each coder began with the raw set of qualitative interview data within NVIVO and worked independently through the first and second steps described above. Calculations of inter-coder reliability, performed within NVIVO, for descriptive codes resulted in an average kappa score of 0.52 and a high agreement level – suggesting that both coders agreed on the main thematic content within the data. The determination of inter-coder reliability was undertaken to ensure that the findings of qualitative analysis were reliable and free from perceptions of bias (Pope et al. 2000). Such measures are becoming more common in mixed methods and qualitative health research and are commonly included in international best-practice guidelines for the analysis of interview data (Morse 2015).

Results

Dementia Prevalence and Costs

An examination of electronic patient records ($N = 2405$) identified 179 people aged 55 years and older who were admitted to the regional hospital over a 3-month period in 2014 with a diagnosis of dementia in their electronic health record (as either a primary admission or co-existing diagnosis). Despite a low recorded prevalence, people who were admitted with dementia attracted a significantly higher cost of treatment ($Mdn = \text{AUD } \$9625$) when compared to age-matched individuals who did not have dementia ($Mdn = \text{AUD } \$5879$), $U = 95,505$, $z = -7.25$, $p < 0.001$. There was also a statistically significant increase in length of stay between

Table 1. Demographic characteristics of 3-month hospital admissions for Tasmanian adults aged 55 years and older

Demographic characteristics	Winter 2014 (<i>N</i> = 2405)
Mean age	73.48 years
Sex	
Male	50%
Female	50%
Dementia as primary admission (total sample)	24 records
Dementia as a previously diagnosed condition in electronic record (inclusive of primary admissions)	179 records
55–64 years of age	4 records
65–74 years of age	16 records
75–84 years of age	79 records
85 years of age and older	80 records
Most common presenting complaint (total sample)	Chest pain (undifferentiated)
Most common presenting complaint for people with pre-existing diagnosis of dementia	Pneumonia (lobar and aspiration)
Deaths during hospitalisation	85 records

people with a dementia diagnosis (*Mdn* = 5) and older people with no diagnosis (*Mdn* = 2) over the same period, $U = 106,014$, $z = -6.11$, $p < 0.001$. Neither age ($r = -0.03$, $p = 0.75$) nor death during hospitalisation ($r = 0.05$, $p = 0.58$) was associated with a higher cost of treatment for people with diagnosed dementia (Table 1).

Clinical Staff Respondents

During 2015, 50 individuals completed the online dementia knowledge survey (33% response rate) to determine individual understanding about the condition. Among this cohort, 13 clinical staff consented to participate in a semi-structured interview by opting for follow-up communication with the researcher at the end of the survey. Compared to the overall population of regional hospital staff in Australia, the survey sample cohort

($n = 50$) had a proportionally higher number of allied health professionals, including those who provided rehabilitation and support services for older adults in the hospital (occupational therapists, physiotherapists, social workers and support workers) (Table 2).

Table 2. Demographic characteristics of clinical hospital staff respondents ($n = 50$)

Demographic characteristics	Tasmanian study (2014)	Tasmanian publically funded hospitals (2014–2015)
Mean age	44 years	46 years
Sex		
Female	36 (72%)	8842 (75%)
Male	14 (28%)	2984 (25%)
Clinical occupation		
Nurse	12 (24%)	3641 (36%)
Medical (specialist or resident)	12 (24%)	921 (9%)
Allied health	21 (42%)	1247 (12%)
Occupational therapist	6 (12%)	4276 (42%)
Physiotherapist	6 (12%)	
Social worker	6 (12%)	
Support worker	3 (6%)	
Other (e.g. anaesthetist, radiotherapist)	5 (10%)	
Provides care to people with dementia as part of employment	43 (84%)	-
Has a family member with dementia	25 (50%)	-
Highest completed education		
Undergraduate degree	27 (54%)	
Post-graduate degree	15 (30%)	
Other completed education	4 (8%)	
Certificate or apprenticeship	3 (6%)	
High school graduate	1 (2%)	-
Completed formal dementia education	21 (41%)	-

Knowledge of Dementia

On average, respondents answered 63% of DKAS items correctly. DKAS scores ranged from 18 to 54 (range = 36) with a median value of 36 out of a possible total score of 54 among clinical respondents. Only 1 out of 50 respondents achieved a perfect score on the DKAS. Inspection of the 5% trimmed mean (34.06) indicated that outlier values did not have an appreciable influence on the mean DKAS score ($M = 34.30$, $SD = 9.50$), which suggested that the results were unaffected by extreme high and low scores. Individual item scores were assessed to identify where knowledge was, on average, stronger or weaker among the sample of clinical staff within the regional hospital. Each item was scored out of 2.00 with higher scores indicating greater alignment with an ideal correct response. Item responses suggested that participants had low levels of knowledge in the specific areas of dementia typologies, symptoms, behaviours and risk factors. Item scores are presented in detail in Table 3.

Semi-Structured Interview Responses

Five disciplines were represented among the 13 respondents who participated in a 30-minute, semi-structured interview. Participants included a geriatrician, a medical registrar, two occupational therapists, two social workers, three physiotherapists and four registered nurses. All respondents worked closely with older adults on geriatric wards, in the emergency department, or in rehabilitation and support services. Thematic analysis revealed one overarching theme referred to here as *obstacles to the provision of dementia care* and five sub-themes: *knowledge, training and attitudinal deficits; limited cognitive screening; dementia un-friendly environments; staff shortages and outsourcing care; and discontinuity of care.*

Obstacles to Dementia Care

During the interviews, clinical hospital staff reported that dementia, while increasingly prevalent among older adults, is seldom a primary reason for admission in the hospital, which was reinforced by data obtained from in-patient electronic records (Table 1). Commonly articulated staff sentiment included the following:

Table 3. DKAS items ordered from lowest to highest by mean scores (0.00 – 2.00)

Scale items	Respondent scores
Blood vessel disease (vascular dementia) is the most common form of dementia [FALSE].	37% correct ($M = 0.74$; $SD = 0.78$)
Uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs [TRUE].	42% correct ($M = 0.84$; $SD = 0.65$)
Movement is generally affected in the later stages of dementia [TRUE].	47% correct ($M = 0.94$; $SD = 0.79$)
Having high blood pressure increases a person's risk of developing dementia [TRUE].	49% correct ($M = 0.98$; $SD = 0.80$)
Maintaining a healthy lifestyle does not reduce the risk of developing the most common forms of dementia [FALSE].	54% correct ($M = 1.08$; $SD = 0.60$)
Alzheimer's disease is the most common form of dementia [TRUE].	55% correct ($M = 1.10$; $SD = 0.81$)
Medications are the most effective way of treating behavioural symptoms of dementia [FALSE].	58% correct ($M = 1.16$; $SD = 0.68$)
People experiencing advanced dementia often communicate through body language [TRUE].	59% correct ($M = 1.18$; $SD = 0.69$)
The sudden onset of cognitive problems is characteristic of common forms of dementia [FALSE].	60% correct ($M = 1.20$; $SD = 0.64$)
Most forms of dementia do not generally shorten a person's life [FALSE].	62% correct ($M = 1.24$; $SD = 0.62$)
It is important to correct a person with dementia when they are confused [FALSE].	63% correct ($M = 1.26$; $SD = 0.66$)
Symptoms of depression can be mistaken for symptoms of dementia [TRUE].	64% correct ($M = 1.28$; $SD = 0.57$)
Early diagnosis of dementia does not generally improve quality of life for people experiencing the condition [FALSE].	64% correct ($M = 1.28$; $SD = 0.67$)
Most forms of dementia reduce the length of a person's life [TRUE].	65% correct ($M = 1.30$; $SD = 0.74$)
Exercise is generally beneficial for people experiencing dementia [TRUE].	66% correct ($M = 1.32$; $SD = 0.55$)

(Continued)

Table 3. (Continued)

Scale items	Respondent scores
Daily care for a person with advanced dementia is effective when it focusses on providing comfort [TRUE].	66% correct ($M = 1.32$; $SD = 0.55$)
Difficulty eating and drinking generally occurs in the later stages of dementia [TRUE].	67% correct ($M = 1.34$; $SD = 0.66$)
Dementia is a normal part of the ageing process [FALSE].	68% correct ($M = 1.36$; $SD = 0.48$)
A person experiencing advance dementia will not generally respond to changes in their physical environment [TRUE].	68% correct ($M = 1.36$; $SD = 0.63$)
It is impossible to communicate with a person who has advanced dementia [FALSE].	68% correct ($M = 1.36$; $SD = 0.63$)
People experiencing dementia often have difficulty learning new skills [TRUE].	71% correct ($M = 1.42$; $SD = 0.54$)
People with advanced dementia may have difficulty speaking [TRUE].	71% correct ($M = 1.42$; $SD = 0.57$)
Dementia does not result from physical changes in the brain [FALSE].	75% correct ($M = 1.50$; $SD = 0.58$)
People experiencing dementia do not generally have problems making decisions [FALSE].	75% correct ($M = 1.50$; $SD = 0.54$)
People with dementia are unlikely to experience depression [FALSE].	76% correct ($M = 1.52$; $SD = 0.54$)
People can recover from the most common forms of dementia [FALSE].	78% correct ($M = 1.56$; $SD = 0.50$)
Planning for end of life care is generally not necessary following a diagnosis of dementia [FALSE].	82% correct ($M = 1.64$; $SD = 0.60$)

Dementia as a presenting problem is very rare ... It's more common to see falls, acute confusion in addition to dementia, or it might be one of their other comorbidities that they're presenting with - then at the end you might also have dementia in the triage. (Jill, Female, Allied health worker)

As addressed above, rather than dementia being a primary admission, it is more common for a person with the condition to present to the emergency

department with an acute event potentially resulting from the progression or exacerbation of underlying dementia pathology. Addressing the complexity of dementia-related admissions a respondent stated, "In patients with dementia, pneumonia, urinary tract infections, falls, and unconscious episodes are very common ... A consequence of complex admissions is that these patients are often also delirious" (Rodney, Male, Medical Doctor).

The complexity and perceived resource requirements associated with dementia-related admissions meant that some hospital staff were either unaware of, or avoided engaging with, underlying cognitive impairment in their treatment of a vulnerable older person. Instead, clinicians appeared to focus predominantly on the presenting complaint without broader concern for underlying issues. Staff members stated,

We are so focussed on just treating what the person [with dementia] is admitted for. We treat them for the fractured hip, the hip gets fixed, and then we say, 'you can go home.' No one is considering other diagnoses [such as dementia] ... because that just opens so many doorways. (Nancy, Female, Allied Health Worker)

If you have someone admitted with dementia to one of the medical-surgical wards, nurses take very little time to engage with the individual to find out about them. They just see them as a problem...There's almost a culture that people with dementia don't belong anywhere else in the hospital and that then affects how they are treated. (William, Male, Nurse)

There was an overarching sentiment among hospital staff that dementia was not perceived as a major or imminent challenge, even when it created significant complexity and comorbidity among older adult admissions. Staff identified a range of interpersonal and organisational barriers that compounded care difficulties and resulted in potentially suboptimal care, poor discharge planning and limited engagement with the person living with dementia.

Knowledge, Training and Attitudinal Deficits

Respondents who frequently worked with older adults reported gaps in dementia knowledge among general staff and poor attitudes during interpersonal communication with people who have dementia. Congruent with the DKAS results, respondents spoke about challenges identifying

dementia typologies and symptoms: "In terms of staff knowledge around dementia, there are certainly big gaps even around the different types of dementia and behaviours associated with it" (Jill, Female, Allied health worker). Clinical staff reported that an observed lack of knowledge among the regional hospital workforce was potentially underpinned by limited professional training opportunities for people to learn about dementia symptomatology and care: "There's no formal education about how to manage people with dementia or problems they might have" (Luke, Male, Medical Doctor). A lack of knowledge about dementia, particularly the diversity of symptoms, was reportedly associated with poor interpersonal communication between clinical staff members and people with dementia. In particular, staff members who were unfamiliar with dementia often reacted to cognitively impaired patients as though their behavioural symptoms were deliberately disruptive. Respondents asserted,

People [who work in the hospital] don't really understand dementia at all... you hear some of the language and you just cringe because [the staff member is] showing that they don't understand...When you hear them speaking to people, it's like [people with dementia] are being naughty children. (Tessa, Female, Nurse)

There's a lack of understanding [about dementia] by some staff...An example, we had a non-verbal patient who had delirium and I heard one of the older nurses saying, 'Talk to me properly. You know how to talk.' Those sorts of things really worry me. (Richard, Male, Allied health worker)

Limited Cognitive Screening

The under-diagnosis of dementia poses problems for clinical staff within the hospital. If dementia is not explicitly identified upon admission, then the quality of the patient's hospital experience can be adversely affected. As one respondent noted,

As a group of geriatricians, we've identified that the emergency department is a great area of need [for improved cognitive care]. Cognitive impairment is often under-diagnosed, both dementia and delirium, in that environment and those people are probably at the greatest risk and aren't being picked up early. (Rodney, Male, Medical Doctor)

One of the aims of staff working in the emergency department is to identify older adults who might require additional or specialised care

because of age-related vulnerabilities, such as dementia. Screening for people with dementia was identified by clinical staff as an important action that should ideally be undertaken during initial admission as a means for improving hospital care and discharge planning. It was identified, however, that such screening did not occur routinely: "Cognitive screening isn't done as often as it could be and that can have a big impact on people's safety" (Luke, Male, Medical Doctor). Another interviewee reported, "It only takes five minutes just to do the Mini-Cog [cognitive assessment], but a lot of pre-admissions staff are very busy people and hospitals are very busy places, so it's hard to get that screening happening" (Ellen, Female, Nurse).

Dementia Un-Friendly Environments

People with dementia who are admitted to hospital often present to the emergency department with an acute illness or injury, which may be associated with the underlying pathology of the syndrome. Clinical staff reported that neither the emergency department nor the general wards of the regional hospital were suitable care settings for people with dementia. A clinical staff member reported, "The environment isn't conducive to someone who might have difficult behaviours. It's a stimulating environment. It's noisy, open, and chaotic at times, and that has an impact on the patient" (Lisa, Female, Allied health worker). Another staff member stated, "The environmental factors aren't good in the Emergency Department ... I think the environment itself is probably the most challenging in terms of people with behavioural issues" (Jill, Female, Allied health worker).

Despite recognition of the inappropriateness of hospital environments for the well-being of vulnerable patients, staff reported that a best-practice dementia-friendly environment had previously been implemented in a section of the emergency department. This area, however, was subsequently discontinued for several reasons, with the space reassigned for other purposes. The dementia-friendly space had been designed to be non-threatening and familiar, with medical equipment hidden from view, pictures hung on the walls and comfortable chairs provided for patients and their relatives. This sort of environment is not just useful for behavioural management but also for quality of care,

reduction in stress and confusion and facilitating assessment. A clinical staff member stated,

We had a dedicated dementia unit for patients and staff ... It doesn't exist anymore, which is disappointing because that environment was much nicer and less distressing for individuals with dementia ... Some people thought they were in their homes. One older woman told me to go and make myself a cup of tea in the kitchen. It obviously was not clinical and it didn't look like a hospital and wasn't as noisy. (Jill, Female, Allied health worker)

Staff Shortages and Outsourcing Care

Staff shortages and managerialism were identified by respondents as factors that increased pressure on clinicians and potentially threatened care provision for people with dementia. Respondents contended, "There's no additional staffing given for [people living with] complex, high-end dementias" (William, Male, Nurse), and "We are very understaffed now and we noticeably get more referrals with complex comorbidities, including dementias (Anna, Female, Allied health worker)."

Because of staff shortages and increasing admissions among people with dementia (either diagnosed or suspected), some respondents argued that the hospital recruited people with lower skill levels from external agencies to supervise people with cognitive impairment and reduce the risk they posed to themselves or other patients. This approach to hospital-based dementia care was itself perceived as a risk by some respondents. A staff member reported,

We normally use an outside agency. We call them 'sitters' ... They free the nurses up to have more time to do their clinical duties. It's not possible to have a nurse doing that [supervision], and that's where there's risk for older people in hospital. (Sally, Female, Nurse)

The low level of training among "sitters" was identified as a risk to patient safety and best-practice dementia management. One respondent spoke about the lack of understanding among low-skilled care staff from external agencies with regards to the management of behavioural symptoms of dementia:

I'm not sure what their [sitters'] level of training is because there was one experience a couple of weeks ago where somebody was wandering and the sitter was just following them around, but it actually needed the nursing care attendant to go and redirect [their behaviour]. (Dannielle, Female, Allied health worker)

Discontinuity of Care

One of the factors that can make a hospital admission challenging for an older person is the diversity of clinicians and settings that a person with dementia is confronted with during his or her stay. The potential for multiple and repetitive assessments across diverse departments combines to make the hospital experience uncomfortable and confusing for a person with dementia. A clinical staff member noted, "[The hospital experience] is hard for those with cognitive decline. They need consistency and familiarity. Different people coming in and retelling the same clinical information is obviously not a good patient journey for them" (Dannielle, Female, Allied health worker).

One of the challenges affecting continuity of care is the limited clinical history taking and information sharing that could improve a patient journey through the hospital system. If information is not obtained during initial assessment and early admission, time pressures and imperatives to free bed space for more conventional acute care patients may contribute to clinicians' not adequately investigating a patient's health history. One respondent described the problematic patient journey:

If a person with dementia is admitted, they could arrive at the ward at any time and sometimes the handover doesn't state whether they've had anything to eat or drink, and they get moved around, especially people who have dementia - it's dreadful. They get moved from ward to ward ... It's really confusing. (Tessa, Female, Nurse)

Another staff member spoke about a failure of some clinicians to seek out or access clinical history and goals of care, which could improve care quality for the person with dementia:

Sometimes we don't get information about [a patient's] level of dementia. It could be anything from early dementia to severe ... Sometimes the doctors in the team won't ring the nursing home and that makes it difficult to look at goals of care as soon as [people with dementia] hit the hospital. (Ellen, Female, Nurse)

Discussion

In this study, the recorded prevalence of dementia as a primary reason for admission at a large regional hospital was found to be low among adults aged 55 years and older (<1% of admissions over a 3-month period). Due to the under-diagnosis of dementia in the community, however, and the capacity for the condition to act as a precursor for an acute event (fall) or exacerbation of a chronic condition (aspiration pneumonia) (Kurrle et al. 2012), the true prevalence of dementia-related conditions is potentially greater than admissions data indicate. Internationally, it has been reported that the prevalence of diagnosed dementia is at least 50% lower than the prevalence reported in epidemiological studies (Connolly et al. 2011) or in research that involves direct cognitive assessments of older adults (Sampson et al. 2009). Further, it has been estimated that a quarter of older people accessing acute hospitals are likely to have some form of dementia, although this is often unrecognised (Houghton et al. 2016). Population estimates of dementia suggest that the syndrome is present in at least 5% of the older adult population within Tasmania (Deloitte Access Economics 2011), so there appears to be a discordance between recorded hospital admissions data and estimated population prevalence. Under-diagnosis of dementia was supported by qualitative comments from clinical staff who identified that dementia could be overlooked in the emergency department and hospital wards. Furthermore, it was sometimes viewed as problematic due to the increased demand on limited resources that best-practice management of dementia patients requires.

Despite the low level of recorded prevalence of dementia, costs of treatment and length of stay for a person with dementia were 39% higher for people with a diagnosis of dementia when compared to those who had no diagnosis. National health data reinforce that, across diverse settings, dementia imposes a significantly greater cost and resource burden on the health sector when compared to other conditions (Australian Institute of Health and Welfare 2012). The additional costs imposed by people with dementia in hospital settings are typically due to increased complexity (e.g. challenges imposed by multiple comorbidities and altered behaviours), greater number of investigative procedures, the need for additional human resources to support the person with dementia (such as the “sitters” described in the results section above) and an

increased length of stay that is often associated with the complexity of the admission (Sampson et al. 2006; Zweifel et al. 1999). The present research also found no correlation with either age or death during admission and diagnosis of dementia. This suggests that proximity to death (interpreted by age and death rate during hospital admission) is not confounding the higher costs of dementia-related admissions. The additional costs associated with dementia-related acute care admissions, potential under-diagnosis within the hospital and broader community, and growing prevalence of the condition associated with population ageing, indicate the potential for increases in hospital costs associated with management of the syndrome if current care and treatment practices do not change.

The challenge of managing dementia-related hospital admissions is compounded by limited staff knowledge about the syndrome. Hospital staff displayed a higher level of knowledge about dementia (DKAS Mean = 34.3) than cohorts of family care givers, health students and the general population who have previously completed the DKAS in other studies (Annear et al. 2015). Hospital respondents scored poorly, however, on items that addressed dementia typology, symptoms and optimal care. The DKAS Mean score was also considerably lower than scores recorded among a large population of community nurses ($N = 918$; DKAS Mean = 37.9) who previously completed the 27-item DKAS (Annear et al. 2017). This discrepancy indicates that there is room for improvement in relation to dementia knowledge among hospital staff. Of concern, only 42% of clinical staff correctly identified that uncharacteristic behaviours in a person experiencing dementia are generally a response to unmet needs (Whall & Kolanowski 2004), while only 47% understood that movement can be affected in the later stages of dementia (O'Connor et al. 2010). Such responses indicate that more education is required for hospital staff on the psychosocial and physiological aspects of care for people with dementia. These findings were supported by qualitative reports from staff members who stated that there was a lack of systematic workplace training opportunities to inform care and treatment for people with dementia at a time of increasing community prevalence. Worryingly, staff identified that poor attitudes stemming from a lack of understanding negatively impacted communication with people with dementia, which led to perceptions of poorer clinical care. Evidence from international studies

indicates that negative attitudes towards acute care provision for older adults among hospital staff are often related to low levels of knowledge and, therefore, amenable to educational intervention (MacDowell et al. 1998). Although few studies have examined the efficacy and outcomes of dementia education in acute care settings, research into education programmes for other age-related chronic conditions show positive effects. For example, a systematic Cochrane review of 81 randomised controlled trials that included health professional education examined the impacts of knowledge change and reported significant and positive effects on practice and patient outcomes independent of other influences (Forsetlund et al. 2009).

Environmental and organisational culture factors were also highlighted as barriers to dementia care, with clinical respondents reporting a lack of dementia-friendly environments, outsourcing care for people with dementia, lack of care continuity and limited cognitive screening. The hospital setting presents a confusing and confronting environment for a person with dementia. Admissions to the acute sector often increase the risks of additional cognitive and physical deterioration (Alzheimer's Australia 2014). Dementia-friendly environments are typically defined as systems of support that recognise the experience of the person with dementia and provide assistance to remain meaningfully engaged in everyday life (Davis et al. 2009). Such settings aim to reduce confusion and anxiety, enhance patient understanding of their surroundings, reduce behavioural symptoms and promote optimal physical and cognitive functioning for a person with dementia (Marquardt & Schmiege 2009). Dementia-friendly environments create a milieu that is more inclusive of individuals with serious cognitive problems, which overtly acknowledge the centrality of the broader social contexts that the person with dementia lives and experiences care within (Nolan et al. 2002). The concept of the dementia-friendly hospital includes not only a physical environment that is familiar and supportive but also a well-trained and empathetic staff who understand dementia and person-centred approaches to care. Although the conceptualisation and implementation of dementia-friendly and inclusive environments is a relatively new phenomenon, qualitative evidence suggests that people with dementia and their family members value clinical hospital

environments that are private, quiet, homely, and which provide amenities and comfort (Digby & Bloomer 2014). Moreover, recent research from the United Kingdom has shown that dementia-friendly hospital interventions (changes to ward design, social spaces and sensory gardens) can significantly reduce stress and agitation for older and cognitively impaired patients (Waller & Masterson 2015). The discontinuation of a dementia-friendly space in the emergency department of the regional hospital in this study, which had acknowledged positive effects, suggests that person-centred and best-practice dementia care may not be regarded as a current priority by hospital management.

Lack of care continuity and outsourcing of supervisory responsibilities within the hospital were also reported as disruptive to the patient journey for people with dementia. Respondents expressed concerns about interactions with multiple clinicians, lack of familiar and expert carers, and inconsistent information-gathering procedures during an admission for a person with dementia. Of particular concern, respondents spoke about how reduced staffing levels associated with managerialism (Germov 2005) often left people with dementia under the supervision of poorly qualified “sitters” who were unaware of best-evidence dementia management. Similarly, other studies have identified that hospitals often lack the person-centred care at the clinician or organisational level that is required by people with dementia to ensure appropriate quality of care during a hospital admission (Clissett et al. 2013). In a situation where the environment itself is a source of potential confusion and stress, exposure to an unfamiliar care team may exacerbate the cognitive and physical health of people admitted with dementia.

Suboptimal patient journeys (experiences of hospital care that are less than best-practice expectations) and poor interpersonal care are potentially reinforced by the under-diagnosis of dementia within the hospital and wider health care system. Clinical staff reported there was no systematic approach to screening for people with dementia in the hospital and this was perceived as a threat to the quality of care during admissions and subsequent discharge planning. A lack of screening was compounded by limited information received about a patient from both community doctors and residential aged care facilities. In addition, the sentiment among some respondents was that some staff were not inclined

to address health concerns beyond immediate presenting symptoms that an older adult was admitted for in case it increased admission time and reduced beds available for other patients. Cognitive screening for dementia within hospital settings has been identified as clinically difficult and operationally inefficient by health systems researchers (Laurila et al. 2004), with recorded incidence of the condition seldom matching assessment findings. Deficiencies in cognitive assessment in acute settings are potentially associated with a lack of systematic organisational guidelines, inappropriate clinician expectations or knowledge or views that dementia is not a serious problem requiring immediate attention (even when it may be an underlying cause of the admission) (Laurila et al. 2004). While cognitive screening based on age alone is not appropriate (Boustani et al. 2003), clinical staff felt their colleagues needed to be more attuned to the signs and symptoms of dementia during initial admission. This was considered a particularly important skill among the small multidisciplinary assessment team operating in the emergency department. Among such work teams, rapid triage and cognitive assessment of individuals with suspected dementia was considered to improve patient care and outcomes, although more research is required to substantiate this. Research into multidisciplinary triage and assessment teams should ideally involve a range of clinical stakeholders, including paramedics who may be involved in the transport and initial evaluation of older patients.

Limitations and Future Research

This research was designed to inform a dementia education intervention for clinical hospital staff across regional and remote Australia. Because of this, a large regional hospital was selected as the sampling frame for the initial exploratory study. The convenience sampling approach may have resulted in the selection and recruitment of a motivated sample that had a higher level of dementia knowledge and different experiences of dementia when compared to a large random sample of hospital employees. Moreover, the dominance of allied health professionals in the response cohort contrasts with the broad structure of clinical health service providers in Australia where qualified nurses are the largest workforce group. This is potentially explained by older adult requirements for rehabilitation

and support services following illness or injury necessitating hospital treatment and the associated interest in this research among those who provide this type of care. To address both limitations and verify the current findings, future investigations of hospital staff knowledge and outcomes of admissions for people with dementia should be undertaken employing cluster randomised sampling across multiple regional hospitals in Australia. Work is also currently ongoing to establish normative benchmark scores for the DKAS among different populations (health professionals, students and laypeople). At present, scoring of the DKAS involves an analysis of total score (out of 54), item scores (out of 2) and comparisons with other cohorts of scale completers.

Implications and Recommendations

Although the concept of age-friendly environments has been in use since the early 21st Century (World Health Organization 2007), the notion of dementia-friendly hospitals has only recently emerged as a salient health management issue. Previous international research has reported that creating age-friendly environments in hospitals potentially provides a variety of salient benefits for older patients and the organisation. Potential benefits include reductions in patient anxiety and discomfort, reductions in burdensome and unnecessary medical procedures and tests, improved interpersonal communication between professional staff and patients, better patient handovers and hospital branding and marketing opportunities (Chiou & Chen 2009; Huang et al. 2011).

This research identified several individual, organisational and environmental barriers to the implementation of best-practice models of dementia care. Data derived from this study may help to inform the development of strategies to support better dementia care and treatment and overcome challenges to implementation. Several recommendations can be surmised that aim to improve dementia care and treatment in public health facilities. Firstly, regional and rural hospitals should provide professional development for all clinical staff to improve their knowledge about and attitudes towards dementia, particularly in the areas of best-evidence care strategies and symptom identification. Secondly, it is recommended that a randomised controlled trial be undertaken to explore the efficacy of a dementia-friendly admissions department in relation to

patient stress and agitation, symptom severity, length of stay and treatment outcomes. Finally, to address problems with patient hospital experiences, it is recommended that each new dementia admission be assigned a care manager to plan and guide their hospital stay and ensure that there is good continuity of care and contact with staff who are well-trained in the management of patients with dementia.

Conclusion

Dementia-related admissions comprise a small, but growing, component of care in a large regional hospital. Admissions for people with dementia are complicated by communication challenges and multiple comorbidities that challenge clinician competence during initial assessment and admission. Prevailing under-diagnosis, high costs of current treatment approaches and longer admission periods also necessitate consideration of the obstacles to effective dementia care in such settings. Within the participating regional hospital, clinical staff displayed a moderate level of knowledge about dementia, but specific deficiencies in their understanding of psychosocial care. It is possible that a lack of knowledge about the psychosocial aspects of care influenced staff attitudes towards people with dementia. Barriers to optimal dementia care are a result of environmental factors, organisational culture, and individual clinician knowledge and attitudes. Future studies should evaluate the efficacy of educational interventions with clinical hospital staff as an option for improving care experiences and outcomes.

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Tine Buffel, Sophie Handler and Chris Phillipson (eds.) (2018). *Age-Friendly Cities and Communities. A Global Perspective*. Bristol: Policy Press, 300 pp. ISBN 978 1 4473 3131 5 (hardback)

*REVIEWED by SHYH POH TEO**

The increase in population ageing requires strategic planning to meet the needs of older people. In the past, policy discussions dwell on medical and social support services, long-term care and the financial commitment needed for sustainability. As the majority of older people are active and independent, a more inclusive approach, such as development of age-friendly cities and communities (AFCC), is appropriate to achieve wider reaching benefits through increased participation and quality of life. This book is timely, focusing on these concepts and the “paradigm shift,” which has become an age-friendly movement globally.

This book brings together international expertise to discuss the complex decisions involved in planning AFCCs. An interdisciplinary team, including architecture, urban design, sociology, and social and environmental gerontology, is necessary to take into account considerations

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such as demographic change and the spectrum of older people's needs in communities. The book is relevant to those studying about or engaged in urban development or services for older people.

The intuitive layout is divided into three sections: the first section covers the general principles and considerations required to develop AFCCs, followed by international case studies to illustrate the challenges and opportunities to develop age-friendly policies. The final section describes more advanced and complex application of these concepts, ranging from how to involve architects and artists into age-friendly practices to the additional challenges for older people with visual loss that should be considered in AFCCs. The book ends with a manifesto for change, which serves as a call to action for countries to strive towards age-friendliness.

I enjoyed the narrative and historical perspective of how ageing strategies originated from humble beginnings, later evolving to AFCCs to account for the diversity of ageing experiences. As a novice in social gerontology, I appreciated the gradual introduction to the wide-ranging principles relevant to AFCCs. This included the insightful descriptions of how communities and cities evolve and change due to migration, economic inequalities within cities and displacement of traditional sources of support and how austerity measures affect services. The dynamic interaction of different aspects of the environment, in the immediate vicinity and homes to higher levels of society such as neighbourhoods and cities, and how it shapes an individual's ageing experience are described eloquently. As these factors affect political, economic and other forces beyond a person's community, they exemplify the need not only to focus at the individual level but also to integrate among multiple levels of social organizations.

Case studies were appropriately chosen from countries that have introduced or initiated the process towards AFCCs, which highlight the range of issues described in the first section. The German experience was quite fascinating, with the backdrop of the fall of the Berlin wall and the rapid urban transformation that followed this historical event. A balanced discussion was provided regarding the conflict between economic interests and the needs of an ageing but less affluent population. The Brussels story describes the Active Caring Community project

for frail older people in disadvantaged neighbourhoods. Older people were involved to create a community that supports ageing in place by providing meeting opportunities and enabling residents to know each other. This demonstrated how opportunities can be derived from challenging circumstances, once there is insight into the social dimensions of the environment.

The authors from Hong Kong shared lessons from Asia-Pacific countries, such as Japan, Korea, Thailand, Singapore and China. Within Australia, age-friendly approaches were compared between Sydney, Melbourne and Canberra within state and national contexts. The diversity of experiences was useful to contrast the different backgrounds of each location. Despite this, there is an overall sense that there are similar demographic changes, common problems and solutions to move forward the agenda of AFCCs.

One of the main strengths of this book is the strong research base from which the recommendations are made and how these can be integrated into policy. The research findings from Ireland in implementing AFCCs took the views of local, national and international stakeholders in developing their programme. It was eye-opening to observe that although these groups were involved in the same initiative, their perspectives differed in terms of motivation, actions influencing development of the AFCCs and what issues need to be addressed for the future. Although there is paucity of data on evaluation, this was consistently reiterated as a recommendation for many of the age-friendly initiatives.

As a clinician reading this book, I believe these insights on AFCCs provide richness to my future social considerations. For example, older people may choose to remain in suboptimal housing, due to the proximity of familiar spaces, resources and support services. The awareness to consider broader economic, political and cultural dimensions was heightened, in order to avoid the risk of neglecting factors that are integral to a person's life experience and community life. This book also provided a new perspective on the use of the international guide for developing age-friendly cities (World Health Organization 2007). Instead of following a rigid checklist, emphasis should be placed on the process of involving older people and taking into account the considerations that makes their environment suitable for their needs.

Overall, this book offered much insight into the development of age-friendly initiatives in the community, focusing not just on the environment but also on the broader perspective of involving older people in the process of designing, production and research of their living spaces.

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Torbjörn Bildtgård and Peter Öberg (2017).
*Intimacy and Ageing: New Relationships in
Later Life*. Bristol: Policy Press, 212 pp. ISBN
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REVIEWED by DORA JANDRIC*

In their book *Intimacy and Ageing: New Relationships in Later Life*, Torbjörn Bildtgård and Peter Öberg explore late-life intimate relationships in cross-gender couples, drawing on various international research to show how older people perceive and engage in new relationships in later life. The book is divided into twelve chapters and presents mixed methods throughout, combining quantitative and qualitative data to provide deeper insight into intimacy in later life. The authors divide the book into several thematic units, with the chapters in each unit following the key theme, such as change in structure in late-life repartnering, application of these changes to individual lives and the consequences of these changes. This review will summarise the key points in each chapter, emphasising the contributions this book makes to the area of ageing studies and beyond, and it will offer some potential limitations of it as well.

Chapter one introduces some key ideas that will be discussed later on in the book, such as intimacy, the concept of pure relationships and the shift from a culture of marriage to a culture of divorce. It does so through

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an example of a relationship initialised later in life, after both partners were either divorced or widowed. This chapter also offers an outline of the entire book, summarising the subsequent chapters. Following this introductory chapter are ten chapters that include theoretical and empirical data based on various research from different Western countries, although the case studies presented are drawn from Swedish qualitative and quantitative studies. The final chapter summarises the key points made throughout the book and reflects on the previous chapters.

Chapter two, *Intimacy and ageing in late modernity*, gives a theoretical background to the book by introducing various cultural and institutional changes to the notion of intimacy in contemporary Western societies. The chapter argues that despite most of the Western world's move towards late modernity, relationships in later life will depend on specific cultural and country contexts, as well as on the individual's life course and ageing experience. Chapter three, *The changing landscape of intimacy in later life*, draws on three sets of empirical data, both qualitative and quantitative, and uses the theoretical ideas emerging from Chapter two to show how longevity and the healthy life course affect late-life relationships. The theme of change in late-life repartnering structure is concluded with Chapter four, *From marriage to alternative union forms*, which emphasises the importance of cohort, historical period and life phase for the unions older people choose. For example, the deinstitutionalisation of marriage in recent years has led to a number of new forms of late-life relationships, such as cohabitation or living apart together (LAT), moving away from the norm of marriage.

Chapter five, *A life of relationships*, links the historical transformation of intimacy to late-life relationships using eight examples that represent cohabiting, single, married and LAT individuals. Through their stories, the chapter illustrates how important previous relationships, the way in which they dissolved (widowhood or divorce), and gendered experiences in these relationships are in late-life repartnering. Chapter six, *Attitudes towards new romantic relationships*, asks the questions: "Attitudes to what?" (marriage, dating, LAT, etc.) and "The attitudes of whom?" (men, women, divorcees, singles), in hope to offer a more detailed account of older people's thoughts on new relationships in later life. Using data from the 2012 Swedish survey, the authors create a comprehensive image of a

variety of older people's attitudes towards new late-life relationships, discovering, for example, that living apart together is a preferred union for older people entering in new relationships. Chapter seven, *Initiation and development of new romantic relationships*, completes the second thematic unit that explores how the changes of late modernity apply to individual lives by using four case studies that illustrate the importance of negotiation in late-life relationships. The issues that are most commonly negotiated are same for all types of unions and include autonomy, loyalty towards the former partner, finances and inheritance.

Chapter eight, *A new partner as a resource for social support*, and Chapter nine, *Consequences for social network and support structures*, focus on social support and social networks in later life, and how a new partner might fill those roles. There are three types of support a new partner can offer: companionate support, emotional support and practical support, and once a new relationship is initiated, these roles are often taken away from children and other family members. In terms of consequences for existing social networks, adult children are mostly supportive of their parents' new relationships and, in some cases, even help them set up online dating profiles to make meeting a potential partner easier. Chapter ten, *Sex in an ideology of love*, explores the importance of sex in later life relationships and raises awareness about sexuality in older age. Based on qualitative interviews, the authors conclude that older people are not interested in repartnering if there is no sex involved, thereby dispelling the myth of an asexual older age. Chapter eleven, *Time as a structuring condition for new intimate relationships in later life*, explores the notion of time in late-life relationships, showing how the paradox of having a lot of free time but little time left plays an important role in the formation of new late-life relationships. These relationships are often given different meaning because of the time left in the world for both partners and are more focused on pleasure and enjoyment than on prescribed social norms. Finally, Chapter twelve, *Discussion*, offers a summary of the key ideas, giving a comprehensive overview of the topics and the main thematic issues explored in the book.

Intimacy and Ageing is an important book for anyone working with older people, either in theory or in practice, but it also makes an excellent read for wider audiences, as its straightforward style of writing makes it easy

to follow and understand. The combination of qualitative and quantitative methods adds a depth to the empirical side of the book, and the cases used present good examples of different repartnering experiences. However, the number of cases presented in the book could have been bigger to add some diversity of experiences, as most of the conclusions were based on three or four cases. The final chapter could have provided a deeper discussion and suggested future research paths for exploring intimacy and ageing, instead of offering a summary of the chapters. Overall, this book is a great contribution to the area of ageing studies as it recognises the limitations of research done so far and tries to fill the gaps in our knowledge of late-life relationships.

I J A L

International Journal of Ageing and Later Life

The International Journal of Ageing and Later Life (IJAL) serves an audience interested in social and cultural aspects of ageing and later life development. As such, the journal welcomes contributions that aim at advancing the theoretical and conceptual debate on research on ageing and later life. Contributions based on empirical work are also welcome as are methodologically interested discussions of relevance to the study of ageing and later life.

Being an international journal, IJAL acknowledges the need to understand the cultural diversity and context dependency of ageing and later life. The journal accepts country- or cultural-specific studies that do not necessarily include international comparisons as long as such contributions are interesting and understandable for an international audience.

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