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ABSTRACT

'Choice' is increasingly pursued as a goal of social policy. However the degree to which choice is exercised when entering an informal care role is open to debate. In this study of UK carers, we examined whether caring was perceived as a free choice, and what the consequence of choice was for carers' wellbeing. Our data were derived from responses to a postal survey conducted in a large British city. One thousand one hundred respondents reported providing care to a close person and of these, 72% answered a further set of questions about caregiving and about their own well-being. We found that informal care was generally perceived to be a free choice, albeit in most cases, a choice that was constrained by duty, financial or social resources. Having a sense of free choice in entering care was strongly and positively associated with wellbeing. The positive impact on wellbeing persisted across different measures of wellbeing and when controlling for socio-demographic characteristics and the nature of the caring role. Further work is needed to better understand the modifiable aspects of choice for carers. Nonetheless, this study suggests that enabling individuals to have more choice in their caring roles may improve their lives.

Key words: choice; informal care; motivation; wellbeing; UK

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INTRODUCTION

Rising healthcare costs mean that governments increasingly look to the family for care for individuals, typically older people, unable to look after themselves (HM Government, 2011). Unpaid caregiving (or 'informal care') can be very demanding, often requiring individuals to sacrifice their own health (Pinquart and Sorensen, 2003, Pickard et al., 2000), work (Carmichael and Charles, 2003) and relationships (Pitkeathley, 1989). While many people willingly care for a loved one at times of need, the degree to which they exercise a choice in doing so is open to debate. Given the central role of choice in health (Department of Health, 2010) it is worth considering the degree to which informal care is perceived to be free choice by the individuals concerned.

Broadly speaking, one may take the view that individuals, including carers, make choices that are largely free and rational. Entry into a caring role can be justified in terms of the individual's preferences for caring relative to the alternative(s) (Brouwer et al., 1999). This view is emphasised most notably in economics (Smith and Wright, 1994). 'Rational' entry into caring does not require the carer to secure any financial reward, but it does require them to perceive some personal benefit from caring. Rational and free entry into caring is therefore consistent with theories that the provision of care can be motivated by pleasure or satisfaction. Such rewards may come from altruistic feelings from enhancing the wellbeing of a loved one (Folbre, 1995) the process of caring itself (Brouwer et al., 2005) or feelings of personal accomplishment (Carbonneau et al., 2010). Care could also be argued to be a free and rational choice if there is some expectation of a continuing reciprocal relationship (Folbre, 1995, Walters et al., 2010) or through some anticipation that providing care will ensure the carer's own future care needs will be met, for example, as a result of providing a role model to the carer's own children.

Alternatively, one may take the view that individuals' actions are not free but highly constrained. Care may be provided almost automatically as part of a fulfilment of a social norm. This may come in the form of a moral obligation, a duty or a responsibility to provide care (Twigg and Atkin, 1994, Badgett and Folbre, 1999). Such social norms are assumed to set up expectations about behaviour and may leave little room for manoeuvre, for example in South Asian cultures (Parveen et al., 2011) or amongst women (Badgett and Folbre, 1999). Furthermore, once a caring episode begins, choices will be constrained by myriad factors including the changing needs of the care recipient and the type of care required (Arksey and Glendinning, 2007). Where these social norms are weaker, the state may step in with legislation to codify the obligation to care, regardless of personal preference. In France, for example, the 'obligation alimentaire des enfants à l'égard des parents' codifies the responsibility of adult children towards their elderly parents.

To date, there has been little empirical study of the degree to which family members feel they are exercising choice in taking on a caring role (Arksey and Glendinning, 2007). One recent US study of older carers found under half of carers perceived their care to be a free choice (Schulz et al., 2012). More research has been conducted on the motives for caring. A study of Dutch carers found that the most commonly reported motivation for caring was 'duty' and that other constraints such as being 'the only one...available' were also mentioned as important factors (Brouwer et al., 2005). Cicerelli (1993) found that caregiving was motivated by both a sense of obligation and a sense of attachment; and a stronger sense of obligation was associated with greater feelings of burden. Lyonette & Yardley (2003) found that many working carers felt constrained by feelings of guilt and duty and these factors contributed to the carers' stress. Given the context for informal care, it can be seen that the constraints placed by normative and societal pressures, as well as necessity, are likely to limit objective choice to provide family care, but also that the anticipated rewards of caregiving may lead some to take on the role of carer out of choice.

Our study addresses a gap by simultaneously examining choice and constraints in relation to entering caring. Our objectives were to: (i) establish the degree to which individuals perceive caring to be choice; (ii) identify whether this varies between specific groups of carers; (iii) estimate the impact of exercising choice in caring on the carer's wellbeing. We investigated the issue of perceived choice in caring, using data from a survey of individuals living in a large city in the UK. An important feature of this study is that we also consider individuals with both primary and secondary caring roles.

METHODS

This study is based on data collected through a local government survey of residents' quality of life. The survey covered a range of aspects of individuals' life, including their provision of informal care. The module of questions on informal care included questions about the individual's decision to care; these survey data therefore offered an opportunity to study the decision to care amongst a heterogeneous, group of carers in a community setting. Alongside data on informal care, data were collected on individuals' socio-demographic circumstances and wellbeing and these data were used to examine the factors associated with choice in caring and the relationship between wellbeing and perceived choice in caring. Details of the survey dataset and analysis are reported below.

The Quality of Life Survey

The data used in the study came from the 2009 Bristol City Council Quality of Life Survey (Bristol City Council, 2014). This is an annual postal survey of 25,000 representative residents of Bristol. It covers a range of topics relevant to the local authority, including the individual's local area, home, lifestyle, wellbeing and socio-demographic characteristics. In 2009, respondents were also asked a set of additional questions about any unpaid (informal) care provision. To identify those providing informal care, respondents were asked whether they *"looked after, or gave any help or support to family members, friends, neighbours or others because of long-term physical or mental ill-health or disability, or problems related to old age"*. The full question, provided in supplementary material, closely resembles the question used in the UK population census. Respondents, who indicated that they provided informal care, were asked to complete questions about specific aspects of their care. These covered their caring role, the care recipient's health status, the carer's subjective experience of caring and the decision to provide care. Specifically, individuals were asked whether they agreed or disagreed with four statements: (i) "I had a free choice to provide care"; (ii) "I provide care because it is my duty"; (iii) "There was no-one else to provide care"; and (iv) "There was no money to provide care" (again the full wording is listed in the supplementary material).

Data analysis

To investigate the degree to which caring was perceived to be a free choice, carers were categorised into three groups based on their responses to the four questions about their decision to care. The first group comprised those carers who stated that their care was solely a free choice. The second group comprised those carers for whom informal care was felt to be a free choice, but one that was also constrained by one of the three factors listed (i.e. duty, a lack of support or a lack of money). The third group comprised individuals for whom informal care was not considered to be a free choice. A new three-category variable, capturing 'perceived choice in caring' was created to reflect these three groups.

The first investigation focused on identifying whether perceived choice in caring was affected by socio-demographic factors and the caring role entered into. To examine the effect of socio-demographic factors, we identified variables in the dataset that related to demography (age, sex), culture (religion, ethnicity) and empowerment (qualifications, home ownership, and receipt of benefits). We also identified several relevant care-related variables: the nature of caring role (primary or secondary), the provision of personal care, the health status of the care recipient, and the age of the carer recipient. We used cross-tabulations to explore the magnitude of associations between perceived choice in caring and these variables and, given the ordinal nature of the perceived choice variable, used Kruskall-Wallis tests to identify statistical significance of any associations. As a sensitivity analysis we also ran chi-squared tests, treating the dependent variable as categorical rather than ordinal.

The second investigation focused on the relationship between perceived choice in caring and carers' subsequent wellbeing. We examined individuals' hedonic wellbeing (Kahneman and Sugden, 2005) using two survey questions about their happiness and satisfaction with life. The happiness questions had four possible responses on a Likert scale ranging from 'not at all happy' to 'very happy'. The life satisfaction question was rated from 1 ('completely dissatisfied') to 10 ('completely satisfied'). We examined individuals' eudemonic wellbeing (Sen, 2009) using the ICECAP-O (Coast et al., 2008) capability questions and, for carers, additionally through the Carer Experience Scale (Al-Janabi et al., 2008). The ICECAP-O measure comprises questions about five core capabilities in life and responses can be scored to generate an overall score between 0 (no capability) and 1 (full capability) for the respondent (Coast et al., 2008). The Carer Experience Scale comprises questions about six aspects of care-related quality of life and responses can be scored to generate a score between 0 (worst caring experience) and 100 (best caring experience) (Al-Janabi et al., 2011). The life satisfaction and happiness questions are listed in the supplementary material along with the ICECAP-O and CES items.

The wellbeing data across all measures were non-normally distributed, with most responses bunched towards the higher end of the scales. To analyse the relationship between perceived choice in caring and wellbeing we therefore used Kruskall-Wallis (non-parametric) tests. We then used multivariable regression modelling, to allow for the fact that the relationship between wellbeing and perceived choice in caring may be confounded by other factors. To do this, we modelled individuals' wellbeing responses as a function of the degree of choice in caring ('free', 'constrained' or 'unfree'). We controlled for socio-demographic and care-related factors. We estimated the regression model with the dependent variable being life satisfaction (hedonic wellbeing) and then re-estimated the model using capability (ICECAP-O) scores (for eudemonic well-being).

RESULTS

5771 individuals responded to the survey, of whom 1,100 (19%) indicated that they provided some informal care in a typical week. Of these carers, 793 (72%) answered the question about whether their decision to care was a free choice. The analyses that follow focus on these individuals. To set the sample of carers in context, table 1 shows the characteristics of these carers in comparison with the non-carer survey respondents. In general, carers were similar to the non-carers. In terms of the decision to provide care, more than four-fifths of carers indicated that their decision to care was a free choice, and over half that they cared out of a sense of 'duty'. A minority indicated that no one else was available or that there was no money for paid care.

Table 1: Contextual characteristics of carers and non-carers in the sample (n=5073)

Variable	**Carers (n=793)**	**Non-carers (n=4280)**
Socio-demographic characteristics		
Age (over 65)	21.1%	25.9%
Sex (female)	59.8%	56.6%
Ethnicity (black and minority ethnic)	7.1%	7.6%
Religious	67.3%	62.0%
Formal educational qualifications	77.7%	73.8%
Receive means tested benefit	19.3%	18.9%
Employed full-time	31.4%	38.7%
Home owner	76.3%	72.7%
Care-related characteristics		
Caring role (main carer)	40.5%	n/a
Provide personal care	26.9%	n/a
Care recipient health ('bad' or 'very bad')	36.3%	n/a
Care recipient age (over 65)	67.6%	n/a
Factors related to the decision to care		
It was a free choice	81.8%	n/a
It was a duty	63.5%	n/a
There was no-one else to do it	39.5%	n/a
There was no money for paid care	32.5%	n/a
Wellbeing		
Happiness (% 'very happy' or 'quite happy')	88.8%	90.4%
Life satisfaction (mean, on 0 to 10 scale)	7.14	7.35
Capability (mean, on a 0 to 1 scale)	0.817	0.820
Caring experience (mean, on a 0 to 100 scale)	69.6	n/a

Carers were classified to one of the three categories regarding their perceived choice in caring. Around a third (32.8%) of individuals were in the group that solely indicated that the decision to care was characterised by a free choice (‘free’). Around half (49.0%) indicated that the decision to care was characterised by a free choice but was also constrained by duty, a lack of others to care and/or a lack of money for paid care (‘constrained’). Finally just over a sixth (18.2%) of individuals responded negatively to the question on free choice (‘unfree’).

Table 2 reports the associations between carers’ perceived choice in caring and socio-demographic characteristics of the carer and the caring role entered into. Perceived choice in caring was unrelated to the socio-demographic characteristics of the carer, with none of the associations significant at the 5% level. However, a re-examination of the associations using chi-squared tests revealed two significant associations, with male and ethnic minority individuals being disproportionately likely to see caring as a free choice, albeit constrained (not reported). In contrast, perceived choice in caring was related to most of the characteristics of the caring role. Perceived choice was lower amongst carers who undertook a primary caring role, provided personal care or cared for someone in bad health. Perceived choice was unrelated to the age of the care recipient.

Table 2—Associations between individual characteristics and perceived choice in providing informal care (n=793)

Variable	'Free' carers (n=260)	'Constrained' carers (n=389)	'Unfree' carers (n=144)	Signif. (p-value)
Socio-demographic characteristics				
Age (%65+)	24.4%	19.3%	19.9%	0.44
Sex (% female)	64.6%	52.9%	66.0%	0.59
Ethnicity (% BME)	3.5%	9.7%	6.4%	0.10
Religious (% yes)	68.1%	71.0%	64.7%	0.42
Qualifications (% yes)	76.6%	78.5%	77.0%	0.95
Means tested benefit (% yes)	15.9%	19.7%	24.6%	0.06
Employed full-time (% yes)	32.7%	30.3%	32.1%	0.79
Home ownership (% yes)	77.3%	76.0%	76.1%	0.85
Care-related characteristics				
Caring role (% main carer)	17.9%	46.5%	65.0%	<0.01
Personal care (% providing)	15.6%	29.2%	41.0%	<0.01
Care recipient health (% bad/very bad)	28.8%	34.8%	53.5%	<0.01
Care recipient age (% over 65)	68.6%	70.0%	59.6%	0.43

Note: significance of associations calculated using Kruskall-Wallis test

Table 3 reports wellbeing amongst carers, segmented by perceived choice in caring, and non-carers. For carers, a clear pattern emerges, irrespective of the measure of wellbeing, with increased choice associated with higher wellbeing. In all cases the association between wellbeing and choice in caring was strongly statistically significant ($p<0.01$). Carers who care as a result of a free choice (only) also scored higher than *non-carers* in terms of life satisfaction ($p=0.06$), happiness ($p=0.09$) and capability ($p=0.02$). Conversely, carers who report a lack of a free choice in caring, report levels of life satisfaction ($p<0.01$), happiness ($p<0.01$) and capability ($p<0.01$) below the level reported by non-carers.

Table 3 — Associations between wellbeing and perceived choice in providing informal care

Variable	**'Free' carers (n=260)**	**'Constrained' carers (n=389)**	**'Unfree' carers (n=144)**	***Non-carers (n=4280)***
Happiness (% happy)	93.8%	86.4%	80.4%	*90.4%*
Life satisfaction (mean)	7.54	7.07	6.57	*7.35*
Capability (mean)	0.845	0.810	0.782	*0.820*
Caring experience (mean)	75.4	69.9	61.3	*n/a*

Note: significance of associations calculated using Kruskall-Wallis test

The regression models expressed wellbeing in terms of carers' life satisfaction and carers' capability are shown in table 4 and table 5 respectively. The reported regressions were estimated using OLS for ease of interpretation. As a sensitivity test we also estimated the life satisfaction model using ordered logit and the carers' capability model using a double-censored Tobit (censored at 0 and 1). The results from these estimations were qualitatively very similar to those in tables 4 and 5 and are not reported. The OLS regression models confirm that the strong association between choice in caring and wellbeing persists when controlling for the presence of other contextual variables relating to the characteristics of the carer and the caring situation. Only two of variables related to the caring situation are significant and then only in model 6 where the care recipient's poor health and age exert negative and positive influences respectively.

Table 4: Regression models of the association between life satisfaction and free choice in caring (n=793)

Variable	Model 1	Model 2	Model 3
Socio-demographic characteristics	Not included		
Age (65+)		0.76***	0.82***
Sex (female)		0.24	0.32*
Ethnicity (BME)		-0.70*	-0.61*
Religious (yes)		0.28	0.30
Qualifications (yes)		0.36*	0.44*
Means tested benefit (yes)		-0.63**	-0.44*
Employed full-time (yes)		0.34*	0.33*
Home ownership (yes)		0.46**	0.45*
Care-related characteristics	Not included	Not included	
Caring role (main carer)			-0.06
Personal care (providing)			-0.25
Care recipient health (bad)			-0.24
Care recipient age (over 65)			0.08
Choice in caring			
Unfree	omitted	omitted	omitted
Constrained	0.49**	0.57**	0.44*
Free	0.97***	0.89***	0.72**
R^2	0.031	0.113	0.115
Sample size (n)	782	714	686

*p<0.05 ; ** p<0.01; *** p<0.001

Table 5: Regression models of the association between capability wellbeing and free choice in caring (n=793)

Variable	Model 4	Model 5	Model 6
Socio-demographic characteristics	Not included		
Age (65+)		-0.001	-0.002
Sex (female)		0.003	0.007
Ethnicity (BME)		-0.052**	-0.049**
Religious (yes)		0.020*	0.022*
Qualifications (yes)		0.016	0.024*
Means tested benefit (yes)		-0.036**	-0.032*
Employed full-time (yes)		0.010	0.009
Home ownership (yes)		0.051***	0.050***
Care-related characteristics	Not included	Not included	
Caring role (main carer)			-0.005
Personal care (providing)			-0.005
Care recipient health (bad)			-0.021*
Care recipient age (over 65)			0.015
Free choice			
Unfree	omitted	omitted	omitted
Constrained	0.028*	0.024*	0.020
Free	0.063***	0.054***	0.050***
R^2	0.031	0.112	0.126
Sample size (n)	770	711	683

*p<0.05 ; ** p<0.01; *** p<0.001

Controlling for other factors, the 'boost' to life satisfaction from having a free, albeit constrained, choice in caring was worth nearly half a point, on average, on a 1 to 10 life satisfaction scale. The 'boost' to capability from a free, albeit constrained, choice was worth 0.02 points on a 0 to 1 capability scale. The impact on wellbeing was larger when comparing those with a free and unconstrained choice to care, relative to those carers that reported no free choice. On average, the effect of the free choice resulted in 0.72 point higher life satisfaction scores and 0.05 point higher capability scores.

The value of these effects on wellbeing can be put into context by comparing them with coefficients on variables representing more tangible factors on carer wellbeing. For example, in terms of life satisfaction, the positive impact of free (unconstrained) choice is greater than the positive impact of having educational qualifications or home ownership. In terms of capability, the positive impact of free choice is greater than the positive impact of qualifications and is comparable to the positive impact of home ownership.

DISCUSSION

This study suggests that people often see entry into informal care as *both* a choice and a constraint. In this survey, around half the sample of UK carers described their decision to provide informal care as a free choice but also one constrained by a sense of duty, financial resource, or lack of social support. Contrary to expectations, socio-demographic factors were not related to the perception of choice in caring. Conversely, aspects of the caring role (such as being a primary carer and providing personal care) were strongly associated with less choice. The perception of choice was strongly related to carers' wellbeing, controlling for the fact that those carers who perceived free choice tended to have less demanding caring roles.

The finding that many people perceived some form of constraint in caring is not surprising, given previous research (Brouwer et al., 2005, Parveen et al., 2011, Cicirelli, 1993, Lyonette and Yardley, 2003). However the high proportion of carers who felt their decision was a free choice even though constraints were present is more intriguing. This may reflect the complex reality of the decision to care. It is consistent, for example, with the carer needing to make a series of decisions regarding the choice to care in the face of a range of constraints. People may enter and exit caring, make decisions about how much care to provide and what tasks they can undertake. There may be an element of choice in some aspects of these decisions and not in others. Choices may be made in tandem with those of others including the care-recipient and other family members. Certain family members may be positioned and expected, without discussion, to assume the role. Unfortunately with the data in this study we were not able to study the nuances of the choice process. This would be a productive area for future research, subject to data availability. Nevertheless, our finding that caring is simultaneously both a choice and a constraint highlights the importance of a sense of control; those who perceived themselves to have adopted caring out of choice, even when this was constrained, had greater well-being than those who reported they had had no choice.

The lack of association between perceived choice and socio-demographic characteristics was unexpected. We did not find that perceived choice was any lower for example for women or those with less financial capability. This may be because the perception of choice to provide care is highly subjective and potentially fluid or because choice in caring is more strongly influenced by other lenses such as the relationship between carer and recipient, or the degree of prior attachment. For example, there may be less perceived freedom in the decision to undertake spousal or parental care than care for an elderly relative or friend. We also found that choice in caring was strongly linked with the entry into secondary caring roles, especially where the recipient was not in 'bad' health and when no personal care was provided.

While a positive relationship between choice in caring and wellbeing was expected, the magnitude of the effect found in this study is worth emphasising. Choice in caring seems as important in terms of the carer's wellbeing, if not more so, than 'objective' factors for example whether the carer provides personal care or whether the care-recipient is in good health. Choice in caring may therefore be a valuable target for policy-makers concerned about improving carer wellbeing. Future research might focus on developing an understanding of the degree to which social policy can expand perceived choice in caring and which aspects of choice can and ought to be targeted. They may mean, for example, providing more options for combining formal care with informal care provision for the care recipient.

One of the limitations of this work is the low response rate to the questions about choices and constraints in caring. Some carers may have found these questions difficult to answer or intrusive. This may have created some selection bias which in turn may be another reason for lack of association between perceived choice in caring and socio-demographic characteristics. Qualitative work to understand how best to conceptualise and ask about choices in caring would be valuable, and may enhance the response to questions in future survey work. A further limitation is that the survey questions do not allow us to distinguish carers by their time commitment to caring or whether their caring role has changed over time. As well as examining the nature and degree of the choice in a finer grained manner, future research might focus on understanding the causal mechanism at play in more detail. Longitudinal data that captures perceived choice on entry into informal care would be useful in understanding the causal effect of choice on wellbeing.

In conclusion, this study suggests that, for many, entry into caring is perceived as a choice *and* a constraint. Perception of choice in entering caring is positively associated with wellbeing. Further research is needed to specify the aspects of caring where free choice generates higher wellbeing and whether these can be enhanced by social policy. Nevertheless this study suggests, in general terms, that there may be significant benefits to carers from enhancing their scope for choices in their caring roles.

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