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Are reasons for care-giving related to carers' care-related quality of life and strain? Evidence from a survey of carers in England

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Abstract

In England, choice and control is promoted for service users in relation to social care services. Increased choice and control has also been promoted for unpaid carers, although this is still relatively underdeveloped. There is limited recognition of carers' choice in terms of the decision of whether to provide care. Alongside the promotion of choice and control, there has also been a focus on quality of life as an outcome of social care for care-recipients and their carers. Although it is known that carer choice (in terms of the decision of whether or not to provide care) is related to increased burden and poorer psychological health, there is limited evidence of the relationship between reasons for caring and care-related quality of life (CRQoL) and subjective strain in England. In this study, 387 carers were surveyed across 22 English local authorities between June 2013 and March 2014. Multiple regression analysis explored the relationship between carer-reported reasons for caring and CRQoL and strain, whilst controlling for individual characteristics (e.g. age). Reasons for caring were important predictors of CRQoL and strain. Where people were carers because social services suggested it or the care-recipient would not want help from anyone else, this was related to lower CRQoL. By contrast, where carers took on care-giving because they had time to care, this was significantly associated with better CRQoL. Carers reported greater strain where they provided care because it was expected of them. These findings are relevant to policy and practice because they indicate that, while social care systems rely on carers, the limiting of carers' choice of whether to provide care is related to worse outcomes. Increased awareness of this relationship would be beneficial in developing policy and practice that improves the QoL of care-recipients and also their carers.

KEYWORDS
ASCOT, caregiver, long-term care, quality of life, quality of services

1 | INTRODUCTION

Over the past three decades, there has been a sustained emphasis on individual consumer choice for users of public services in the United Kingdom (Taylor-Gooby, 1998). The promotion of individual choice is advocated as a way of creating quasi-markets for publicly-funded services and to improve the quality and effectiveness of services through competition (Taylor-Gooby, 1998). This consumerist

ideology has been influential in the administration and delivery of a range of public services, including long-term care (Bovaird, 2012). Individual choice is proposed to be a "good-in-itself" due to the assumption that greater choice will allow individuals to improve their personal satisfaction and also influence service provision through the cumulative effect of individuals' choices (Arksey & Glendinning, 2007). Indeed, a key outcome of long-term care valued by adults who use care services is personal choice and control over daily life (Qureshi, Patmore, Nichols, & Bamford, 1998; Vernon & Qureshi, 2000). Although it has also been argued that excessive choice may be detrimental to psychological wellbeing (Schwarz, 2004), long-term care policy in England over the last decade has sought to promote individual choice and control over how needs should be met (Department of Health, 2010, 2017).

This policy focus on choice and control, which is situated within the strategic shift towards personalisation in long-term care, has also been extended to family or friend carers (Department of Health, 2010, 2014; NHS England, 2016); however, this is less well-developed than the narrative of choice and control for adults with long-term care needs (Arksey & Glendinning, 2007; Larkin & Mitchell, 2016). Although control over everyday life rated by long-term care service users and their carers has been a key indicator in the English Adult Social Care Outcomes Framework (ASCOF) from its introduction in 2010/11, an indicator to capture carers' perception of involvement and consultation in care-related decisions was only considered from 2012/13 onwards (Department of Health, 2011). In the "Carers' Strategy: Second National Plan 2014–2016," the issue of individual choice and control for carers is framed within the policy strategy of enabling carers to maintain a life alongside caring through personalised support (Department of Health, 2014). Improved information and advice is highlighted as a way of equipping carers with the knowledge required to make critical decisions at transition points, for example, discharge from hospital (Department of Health, 2014), and also to make informed choices in terms of access to long-term care and support services (NHS England, 2016). It is also acknowledged that carers should have a choice of whether to provide care or not, as well as how much or the type of care they will provide (NHS England, 2016).

Beyond the conceptualisation of carer choice as a type of consumer choice in relation to long-term care services, however, there has been limited recognition of carers' initial and ongoing choice to provide care or not in practice (Arksey & Glendinning, 2007). Although this may reflect issues in implementation of policy, it may also be indicative of the inherent tension in allowing carers' greater choice, while also relying on the unpaid care that they provide. The exercise of choice by carers is likely to be problematic if it results in the withdrawal of unpaid care that substitutes for formal long-term care services, especially in the context of increased demand for long-term care due to an ageing population (Arksey & Glendinning, 2007).

Even if it is not widely acknowledged in English carers' policy strategy, personal choice may be exercised in decisions related to whether (or not) to provide unpaid care, initially or at key transition points like hospital discharge, as well as in the decision to access and use formal long-term care services. If we focus on the initial choice to provide unpaid care, personal choice may be influenced by a variety of different factors, which may be broadly grouped into organisational-structural (external) factors and motivational-relational (internal) factors. External factors include, for example, the inadequacy of alternative sources of care, in terms of quality or quantity, and the weighing up of "opportunity costs" between different potential carers that arise from withdrawal from the labour market or foregoing career advancement due to care-giving (Ng, Griva, Lim, Tan, & Mahendran, 2016; Quinn, Clare, McGuinness, & Woods, 2010; Walker, Pratt, Shin, & Jones, 1990).

By contrast, internal factors relate to the carers' personal motivations or relationship between the carer and care-recipient. These internal factors include, for example: the nature and quality of the relationship between the potential carer and care-recipient; personal values, obligation, duty, or guilt, which may be influenced by religious or sociocultural expectations; a desire to reciprocate past help or care received from the care-recipient or someone else; or personal competence and fulfilment in providing care (Cicirelli, 1993; Kuscu, Dural, Yasa, Kiziltoprak, & Onen, 2009; Lee & Sung, 1997; Ng et al., 2016; Quinn et al., 2010; Walker et al., 1990). Internal and external influences on the reasons for providing care are not mutually exclusive. Carers typically report a combination of different internal and external factors that influence their decision to care (Health & Social Care Information Centre, 2010; Kabitsi & Powers, 2002; Romero-Moreno, Marquez-Gonzalez, Losada, & Lopez, 2011; Walker et al., 1990). Importantly, carers may also not experience the "choice" to provide informal care as a free personal choice because of the complete or partial constraints of internal and external factors (Quinn et al., 2010; Romero-Moreno et al., 2011).

Studies have sought to establish whether there is a relationship between carers' reason(s) for caring and their outcomes in terms of subjective burden or strain, psychological health, carer experience,

What is known about the topic

- Social care policy in England seeks to promote choice for service users and carers.
- Carer choice in terms of whether to provide care is often unacknowledged.
- Reasons for providing care are related to subjective burden and psychological health.

What the paper adds

- Caring because of social services' or care-recipients' expectations was related to lower care-related quality of life, which is a key outcome of adult social care.
- Providing care because it is expected of the carer was related to greater carer strain.
- Increased awareness of the relationship between carers' reasons for caring and outcomes may usefully inform policy and practice that seeks to improve carers' quality of life.

or quality of life. A study of adult daughters caring for their elderly mothers, for example, found that the intrinsic factors of filial attachment and filial obligation were both related to the amount of care provided; however, higher attachment was related to lower subjective burden, while higher obligation was related to higher subjective burden (Cicirelli, 1993). Other studies also support the finding of a relationship between reasons for caring and carer outcomes. Lyonette and Yardley (Lyonette & Yardley, 2003) found that extrinsic sociocultural pressures (e.g. carer guilt, others' disapproval, and/or the care-recipient's expectation of care) were the most significant predictors of carer stress, along with the quality of the relationship with the care-recipient. Higher levels of carer obligation have also been found to be related to dysfunctional thoughts (e.g. that carers should dedicate themselves entirely to the care of their relative) and also, indirectly through these dysfunctional thoughts, carer-reported symptoms of depression (Losada et al., 2010). A longitudinal study found that male carers—but interestingly, not female carers—who reported caring because of the perceived value of caregiving and/or expression of love and respect for the care-recipient, rather than extrinsic reasons like guilt or avoidance of disapproval, reported lower levels of depression (Kim, Carver, & Cannady, 2015). It has also been found that carers who experience low levels of personal choice (intrinsic motivation) and high levels of constraint on choice due to internal or external factors (extrinsic motivation) are at greater risk of negative outcomes in terms of anxiety, depression, and anger (Romero-Moreno et al., 2011). In the context of England, a recent study also found that a free choice to care was associated with life satisfaction, capability wellbeing, and positive carer experience (Al-Janabi, Carmichael, & Oyebode, 2017).

Although these studies have explored the relationship between carers' reasons for providing care and their outcomes in terms of quality of life, carer experience, subjective burden, and psychological health more generally, in the context of English long-term care, however, there is little evidence of the relationship between carers' reasons for caring and carers' care-related quality of life or subjective strain. This presents a gap in the evidence, especially in England, where the Care Act (2014) places responsibility on local authorities to address carers' needs and quality of life outcomes through their commissioning, management, and oversight of long-term care services. The impact of policy and practice on carers' choice and its potential relationship to carers' care-related quality of life, which is a key outcome used to evaluate the long-term care system in England (Department of Health, 2017), is unknown. This study, therefore, aims to establish whether reasons for caring, defined in terms of the initial decision to provide care, are important predictors of care-related quality of life and carer strain.

2 | METHODS

2.1 | Participants

Unpaid carers were identified through a survey of adults with care needs related to physical disability, sensory impairment, mental health problems, or intellectual disabilities and who used community-based services in 22 English local authorities between June 2013 and March 2014. The survey was part of a study of care-related quality of life of adults who use care services and their carers in England, which has been reported elsewhere (Forder et al., 2016; Rand, Malley, Forder, & Netten, 2015).

Long-term care service users who participated in a face-to-face or telephone interview were asked to report whether they needed help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs) using the social care for older people aged 65+ questionnaire (Blake, Gray, & Balarajan, 2010) and, if they needed help, whether they received any support and from whom. At the end of the interview, the service user was asked whether they agreed to pass on a letter of invitation to participate to the friend or relative who was reported by the service user to have provided the greatest number hours of unpaid care in the past week.

In the survey, a total of 739 of the 990 service users reported that they had received unpaid help with I/ADLs. In 510 cases (69.3%), the service user agreed to pass on the study information onto the carer. Of these, a total of 387 (75.7%) eligible carers completed an interview.

2.2 | Data collection

Face-to-face or telephone interviews were conducted between June 2013 and March 2014. Written or verbal informed consent was obtained before the interview.

The study was approved by the social care research ethics committee in England (12/IEC08/0049).

2.3 | Analysis

Descriptive statistics were calculated for the sample. The association between reasons for providing care and carer quality of life and strain were explored using regression analysis. The regression models were estimated using Ordinary Least Squares (OLS). The dependent and independent variables considered in these regression analyses are outlined below.

In all analyses, a p value of less than 0.05 was considered to be statistically significant.

Analyses were performed in Stata version 13.

2.3.1 | Dependent variables

Two regression models were estimated with the ASCOT-Carer index and Carer Strain Index (CSI) as the dependent variables. The CSI is a measure of strain related to care-giving based on a 13 item self-report questionnaire (Robinson, 1983). The items capture aspects of care-giving strain, including: sleep disturbance; emotional, family or adjustments; feeling overwhelmed; demands on time; inconvenience; restrictions on daily life or personal plans; physical or financial strain; or the emotional impact of changes in the care-recipient due to ill-health or behaviour(s)

that the caregiver finds difficult. The carer rates whether (1) or not (0) they have difficulties with different aspects of care-giving. The CSI is calculated from the sum of the score for each item, from 0 (no difficulties) to 13 (difficulty with every aspect). The ASCOT-Carer interview (INT4) is a measure of care-related quality of life (that is, aspects of quality of life, beyond health, that may be influenced by long-term care services and are valued by carers) (Rand & Malley, 2014; Rand et al., 2015; Rand, Malley, & Netten, 2012). The ASCOT-Carer (Rand & Malley, 2012; Rand et al., 2015) is an extended version of the Carer CRQoL (Fox, Holder, & Netten, 2010; Malley, Fox, & Netten, 2010). It is included as an overarching outcome indicator in the English Adult Social Care Outcomes Framework (ASCOF) (Department of Health, 2017). The instrument includes seven items to capture the following CRQoL attributes: Control over daily life; Occupation ("doing things I value and enjoy"); Social participation and involvement; Self-care; Personal safety; Time and space to be myself; and Feeling supported and encouraged in the caring role. Each of the seven ASCOT-Carer items is rated by the carer as the ideal state (highest QoL) (3), no needs (2), some needs (1) or high-level needs (lowest QoL) (0). The sum of item scores forms a scale of carer CRQoL from zero (lowest QoL) to 21 (highest QoL).

2.3.2 | Independent variables

The independent variables included the reasons for providing care considered in this study. These variables were generated from responses to a questionnaire item from the 2009/10 survey of carers in households (Health & Social Care Information Centre, 2010), which allowed the respondent to indicate multiple reasons for providing care from a list of nine options (see Table 2.).

The other independent variables considered in the regression analyses were selected to control for factors known to be related to carer CRQoL and strain based on review of the literature (Rand & Fox, 2012). These factors include the following individual characteristics of carers: gender, age, employment status and self-rated overall health. Studies have shown that female carers report higher levels of emotional distress, depression, and strain than male carers (Greenwood, Mackenzie, Cloud, & Wilson, 2008; Molloy, Johnston, & Witham, 2005; Pinquart & Sorensen, 2006; Schoenmakers, Buntinx, & Delepeleire, 2010), that carers in retirement or who do not work report better outcomes than those in employment (Greenwood et al., 2008; Kitrungrote & Cohen, 2006) and that older age is related to lower carer strain (Greenwood et al., 2008). General health has been found to be positively related to carer well-being and quality of life (Kitrungrote & Cohen, 2006; Salter, Zettler, Foley, & Teasell, 2010).

Other variables in the analyses included factors related to the care-recipient, which were collected from the care-recipient interview (care-recipient self-rated health, I/ADLs with difficulty) or carer interview (the carer's report of whether the care-recipient was disorientated or not). Studies have found a relationship between the health and cognitive functioning of care-recipients and carer strain or wellbeing (Greenwood et al., 2008; McKeown, Porter-Armstrong, & Baxter, 2003; Pinquart & Sorensen, 2006; Schoenmakers et al., 2010; Sorensen, Duberstein, Gill, & Pinquart, 2006). Related to these factors are variables related to the type and intensity of unpaid care: for example, co-residence of the carer and care-recipient; estimated hours of care per week; and personal care tasks or administering medicines. The quality of life reported by carers has been found to be associated with the duration and also intensity of care (McKeown et al., 2003; Mockford, Jenkinson, & Fitzpatrick, 2006; Pinquart & Sorensen, 2006). The analysis considers personal care and support with medical interventions because studies have identified carers' experience of these tasks as especially burdensome or emotionally stressful (Stenberg, Ruland, & Miaskowski, 2010). As coresident spousal carers have been found to experience higher levels of depression and burden than adult child carers, we also considered the coresidence (Pinquart & Sorensen, 2006). (The relationship with the care-recipient was not also included in the model because of collinearity with coresidence).

Finally, we controlled for the mode of administration of the interview (i.e. by telephone or face-to-face) because it may result in systematic bias due to social desirability bias or other factors (Bowling, 2005). In another study based on the sample analysed here, it was found that carers interviewed by telephone reported lower quality of life compared to those who completed the interview face-to-face (Rand et al., 2015).

3 | RESULTS

The sample characteristics are reported in Table 1. In the study sample, 228 (58.9%) of the 387 participants in this study were women, which is comparable to the estimate that 60% of carers in England are women (Health & Social Care Information Centre, 2010). Similarly, 10% of the sample were from black and minority ethnic backgrounds, which compares to an estimated 8% of carers in England (Health & Social Care Information Centre, 2010). The age profile of the study sample is, however, older than the general population of carers; 43% of the sample were aged 65 years or older, which compares to an estimate that 25% of carers in England are aged 65 or over (Health & Social Care Information Centre, 2010). Likewise, carers in full-time or part-time employment represent only 26% of the study sample, whereas around half (46%) of English carers are in employment with the majority in the age range of 45–64 years (42%) (Health & Social Care Information Centre, 2010). Just over half of the study sample were caring for their spouse or partner, while only 18.6% were adult sons or daughters caring for a parent. By contrast, carers in England most commonly care for a parent (33%) or spouse or partner (26%) (Health & Social Care Information Centre, 2010). The method of recruitment of carers via service users may have contributed to an oversampling of coresident carers, who are more likely to be looking after a spouse than noncoresident carers (Health & Social Care Information Centre,

TABLE 1 Sample characteristics

	Frequency (%)
Characteristics of the carer	
Gender (male)	159 (41.1)
Age (≥65 years)	166 (42.9)
Ethnicity (white)	348 (89.9)
In paid employment	102 (26.4)
Relationship to care-recipient: spouse or partner[a,b]	178 (50.3)
Self-rated health (bad or very bad)	64 (16.4)
Characteristics of the care recipient	
Self-rated health (bad or very bad)[b]	106 (27.4)
Disorientation[b]	180 (46.5)
Care-related characteristics	
Carer and care-recipient live together	90 (23.3)
Duration of caring (≥10 years)	203 (52.5)
Hours of care (≥10 hr/week)[b]	330 (85.3)
Provides personal care	256 (66.2)
Provides support with medicines	272 (70.3)
Survey administration	
Interview by telephone	51 (13.2)
	Mean (range, *SD*)
ASCOT-Carer CRQoL[b]	13.43 (0–21, 4.70)
Carer Strain Index	6.44 (0–12, 3.84)
I/ADLs with difficulty[b,c]	4.98 (0–8, 2.71)

[a]Other relationships include: parent or grandparent (n = 74); sibling (n = 19); child (n = 58); other relative (n = 5); neighbour or friend (n = 20).[b]Missing values. Relationship to care-recipient (n = 33); Care-recipient health (n = 4); Disorientation (n = 2); Hours of care (n = 1); ASCOT-Carer CRQoL (n = 3); I/ADLs with difficulty (n = 5).[c]This scale includes the following I/ADLs: getting around the house; getting in/out of bed or a chair; feeding yourself; dealing with money and paperwork; washing in a bath or shower; getting un/dressed; using the toilet; and washing face and hands.

TABLE 2 Reasons for caring

	Frequency (%)[a]
I was willing or wanted to help	329 (85.0)
It's was expected of me (It's what families do)	311 (80.4)
S/he wouldn't want anyone else caring for them	202 (52.2)
No one else was available	199 (51.4)
I had the time because not working or work part-time	165 (42.6)
S/he asked for my help/care	145 (37.5)
I have particular skills or ability to care	123 (31.8)
I took over caring responsibilities from someone else	49 (12.7)
Social services suggested I should provide care	39 (10.1)

[a]Carers were able to select one or more reason.

2010). This may partly explain the overrepresentation of spousal/partner carers in the study sample.

Descriptive statistics for the carer outcome variables are also presented in Table 1. The distribution of the ASCOT-Carer CRQoL has a slight negative skew with no obvious ceiling effect. The Carer Strain Index distribution is platykurtic without skew or obvious ceiling effect.

Table 2 summarises the reasons for care-giving reported by carers. Of the 387 carers, the majority reported that they were willing or wanted to help (85.0%) and/or it was expected of them (80.4%). The English survey of carers in households 2009/10 also found these two reasons to be the most commonly reported; however, the proportion of the sample reporting these reasons to provide care were much lower than in this study (53% and 54% respectively) (Health & Social Care Information Centre, 2010). Just over half of the respondents stated that they provided care because the care recipients would not want anyone else caring for them (52.2%) or no one else was available (51.4%). The least common reasons for providing care were that the carer took over from someone else (12.7%) or that social services suggested that they should provide care (10.1%). If the reasons to care were considered together, it was found that only 17 respondents (4.4%) reported the sole motivation of being willing or able to help. The majority of respondents (80.6%) reported a constrained choice to provide care (that is, they were willing or able to help but also reported another reason, e.g. no one else available or it's expected of them.

The results of the regression analysis to explore the relationship between reasons for caring and outcomes, whilst controlling for other factors known to be associated with carers' quality of life and strain, are shown in Table 3. For both models, the Ramsey RESET (Ramsey, 1969) and Pregibon link test (Pregibon, 1980) statistics did not indicate omitted variable bias or misspecification error. After controlling for individual characteristics, care context-related factors and survey administration, there were significant associations between reason to provide care and the carer outcome measures considered in this study.

In terms of ASCOT-Carer care-related quality of life, significant negative associations were observed with caring because social services suggested it or the care-recipient would not want support from anyone else. There was also a significant positive relationship between ASCOT-Carer CRQoL and the carer having time to care because s/he was not working. Carer strain was significantly positively associated with caring because it was expected of the carer. Trends towards significance ($p < 0.10$) were also observed with higher care-related QoL for those who reported having the skills or ability to care, lower strain for those who reported caring because they did not work, and higher strain for those who reported social services suggested they should care.

Significant associations were also observed with the independent variables related to individual characteristics, care context-related and survey administration factors, which were considered

TABLE 3 Multiple regression

Independent variable[a]	ASCOT-Carer CRQoL			Carer Strain Index		
	Unstandardised Coeff. (*B*)	95% CI	*p* value	Unstandardised Coeff. (*B*)	95% CI	*p* value
Reasons for caring						
No-one else available	−0.45	−1.27 to 0.37	0.281	0.41	−0.30 to 1.13	0.253
Willing or able to help	0.32	−0.79 to 1.44	0.569	0.78	−0.19 to 1.76	0.114
Not working or work part-time	0.84*	0.01 to 1.67	0.048	−0.65	−1.37 to 0.07	0.077
Particular skills or ability to care	0.87	−0.04 to 1.78	0.060	−0.14	−0.93 to 0.65	0.730
Social services suggested I care	−1.89**	−3.18 to −0.61	0.004	1.00	−0.12 to 2.12	0.081
It's expected of me	−0.09	−1.13 to 0.94	0.863	1.32**	0.41 to 2.22	0.004
S/he wouldn't want anyone else	−1.03*	−1.91 to −0.14	0.023	−0.29	−1.05 to 0.48	0.461
Care-recipient requested my help	−0.45	−1.32 to 0.42	0.307	0.27	−0.49 to 1.03	0.483
Took over from someone else	−0.24	−1.46 to 0.98	0.694	−0.06	−1.13 to 1.00	0.907
Gender (male)	1.53***	0.71 to 2.36	<0.001	−0.99**	−1.71 to −0.28	0.007
Age (≥65 years)	0.13	−0.76 to 1.02	0.774	−0.47	−1.24 to 0.30	0.227
In paid employment	1.02*	0.02 to 2.01	0.046	0.59	−0.28 to 1.46	0.183
Carer health (bad or very bad)	−3.14***	−4.26 to −2.02	<0.001	0.45	−0.52 to 1.42	0.358
Care-recipient health (bad or very bad)	−0.84	−1.78 to 0.11	0.083	0.49	−0.33 to 1.32	0.239
Number of I/ADLs with difficulty [b]	−0.26**	−0.43 to −0.1	0.002	0.30***	0.16 to 0.45	<0.001
Care-recipient is disoriented	−2.04***	−2.83 to −1.24	<0.001	1.49***	0.80 to 2.19	<0.001
Carer and care-recipient live together	−1.08	−2.16 to 0.01	0.051	0.41	−0.54 to 1.35	0.397
Duration of caring (≥10 years)	−0.81*	−1.60 to −0.02	0.046	0.48	−0.21 to 1.16	0.172
Hours of care (≥10 hr/week)	−1.34*	−2.64 to −0.04	0.044	1.05	−0.08 to 2.19	0.069
Carer provides personal care	−0.72	−1.66 to 0.23	0.137	0.69	−0.13 to 1.50	0.099
Carer provides support with medicines	−0.50	−1.46 to 0.46	0.310	1.34**	0.50 to 2.17	0.002
Interview administration: By telephone	−1.54**	−2.69 to −0.38	0.009	1.12*	0.12 to 2.12	0.028
Constant	19.21***	17.42 to 21.00	<0.001	−0.19	−1.76 to 1.37	0.807
N			376			379
ANOVA *F*-test			11.56***			8.03***
Adjusted R^2			0.383			0.290

[a]The *reasons for caring variables* are considered as dummy variables, i.e. *Reason for caring: no one else available* is considered as those who rated this category as one of their reasons for caring compared to those who did not. All of the other variables (except for "number of I/ADLs with difficulty") were also considered as dummy variables to indicate the presence/absence of the specified category. In the case of *self-rated health* (carer, care-recipient), for example, the reference categories are a self-rating of health as ok, good, or very good. The reference categories for the other variables are: *gender* (female); *age* (<65 years); *In paid employment* (not in paid employment, e.g. unemployed, in training, retired; *care-recipient disorientation* (not disoriented); *carer and care-recipient live together* (no, they live apart); *duration of caring* (<10 years); *hours of care per week* (<10 hr); *personal care* (no, carer does not provide personal care); *support with medicines* (no, carer does not provide support with medicines); *administration of interview* (by face-to-face interview).

[b]The number of I/ADLs with difficulty is a scale from 0 (no difficulties) to 8 (difficulty with all eight I/ADLs considered in this study).

*$p < 0.05$,**$p < 0.01$,***$p < 0.001$.

as control variables in the analysis. Consistent with other studies (Greenwood et al., 2008; Molloy et al., 2005; Pinquart & Sorensen, 2006; Schoenmakers et al., 2010), significantly higher care-related quality of life and lower carer strain was found for male than female carers. As expected, a significant predictor of lower carer care-related quality of life was found to be poor health. Likewise, lower quality of life and higher strain were significantly related to care-recipient disability (I/ADLs completed with difficulty) and experience of cognitive impairment (disorientation). Higher intensity care (≥10 hr per week) and longer duration of care-giving (≥10 years) were found to be significantly associated with lower quality of life, while being in paid employment was significantly related to better care-related QoL. As expected based on evidence from other studies of carers who help with administering medicines or medical procedures (Stenberg et al., 2010), helping the care-recipient with medicines was also found to be related to higher carer strain. Finally, again as expected, those carers interviewed by telephone reported lower care-related quality of life and higher strain than those who completed face-to-face interviews. The other independent variables considered in the analysis did not reach significance at the 5% level.

4 | DISCUSSION

This study sought to explore the link between carers' reasons for caring and their care-related quality of life and care-related strain. While it has been recognised that there are positive aspects to the experience of care-giving (Brouwer, Exel, Berg, Bos, & Koopmanschap, 2005; Carbonneau, Caron, & Derosiers, 2010; Cohen, Colantonio, & Vernich, 2002; Grant & Nolan, 1993; Kramer, 1997; Ribeiro & Paul, 2008), measures designed to capture the negative aspects of care-giving, like burden or strain, are still widely used in long-term care research and evaluation. In England, however, the broader construct of care-related quality of life has been identified as a key outcome of the long-term care system in the Adult Social Care Outcomes Framework (Department of Health, 2017). Carer care-related quality of life is an overarching outcome indicator, which captures aspects of quality of life valued by carers and that also may be affected by long-term care support (e.g. carer support groups, short-term breaks) (Netten et al., 2012; Rand & Malley, 2012; Rand et al., 2015). The focus on carers' quality of life outcomes reflects the wider repositioning of carers as co-clients whose own needs and outcomes should be considered by long-term care services (Rand & Malley, 2014). While carers' choice continues to be primarily conceptualised as consumer choice in relation to long-term care services, there has been some recognition that carers should also be able to exercise personal choice in terms of whether and how to provide care (NHS England, 2016

Reasons for caring were found to be important predictors of care-related quality of life, as well as carer strain. External factors indicative of a perceived lack of availability or suitability of other sources of care ("social services suggested it," "s/he wouldn't want anyone else") were related to lower care-related quality of life after controlling for other factors (e.g. health, type of care). The external factor of time to provide care due to the carer not working or working part-time was, by contrast, associated with higher care-related quality of life. There was also a trend towards significance for the internal factor of 'skills or ability to care, which indicates a sense of personal competence and fulfilment in providing care, and higher care-related quality of life. We did not find any significant relationship between personal choice ("I was willing or able to help") and care-related quality of life or carer strain. By contrast, internalised expectation ("it was expected of me") was related to higher levels of carer-reported strain but no significant association was observed with care-related quality of life. This is consistent with other studies that have found a relationship between internalised expectation (obligation, duty or guilt) and carer strain, burden or mental well-being (Cicirelli, 1993; Lyonette & Yardley, 2003; Quinn et al., 2010; Romero-Moreno et al., 2011).

This study has some limitations. The study sample size was limited; therefore, nonsignificant results may be due to insufficient power. We were also unable to run analyses on the subgroup who reported only an intrinsic motivation of personal choice to provide care because of the small number in this subgroup (n = 17). The findings are also based on a data collection from 2013/14. As such, there may have been subsequent temporal shifts due to the impact of the changing policy landscape, for example, the implementation of the Care Act (2014). Further research is needed, therefore, to explore the relationship between reasons for caring and outcomes in a larger sample of carers to explore any potential differences by subgroup of carer including, for example, the type of health condition experienced by the care-recipient, as well as to explore the impact (if any) of the implementation of the Care Act (2014) or other policy trends.

Despite the limitations of the sample, the findings of this study lend support to the extension of the definition of carer choice in policy to consider also the initial choice to provide care (NHS England, 2016). In recognition of the English long-term care system's reliance on unpaid care, policy has focussed on what may be done to support carers in their care-giving role by enabling them to sustain important aspects of life and their own health (Department of Health, 2014). Despite the direction of policy strategy and the Care Act (2014) to conceptualise carers as *coclients* on an equal footing with those they care for (Department of Health, 2014), the practice of adult long-term care continues to primarily regard carers as resources or coworkers (Glendinning, Mitchell, & Brooks, 2015) and tends to overlook carers' opinions, needs, and outcomes (Brooks, Mitchell, & Glendinning, 2016). Although there are complex relational and organisational factors that affect carers' ability to choose whether or not to care (Arksey & Glendinning, 2007), the finding that the reasons to provide care are related to carers' care-related quality of life, as well as carer strain, suggests that carers' reasons for providing care should also be considered by long-term care policy and practice.

Based on the findings presented here, it could be argued that there should be greater awareness of how organisational factors (for example, perceptions of the availability of services, the attitude of

professionals towards carers, and provision of long-term care support for carers) may influence carers' outcomes in terms of care-related quality of life. This is consistent with qualitative evidence that carers' experience of whether and how long-term care services affect their care-related quality of life is influenced by their experience of barriers to accessing services. These barriers include difficulties in making initial contact with adult social services, not qualifying for support due to eligibility criteria, or deflection from one service to another (Rand & Malley, 2014). In practice, for example, it may be beneficial to raise awareness through training of the potential negative effect of attitudes expressed by professionals that carers "ought to" provide care. It also highlights the potential cost of policy that promotes family care through appeal to (legal, social or moral) duty, obligation, or responsibility. Even if long-term care systems rely on informal care, the availability (…) or, at least, the perception of availability, if needed (…) of formal support may promote carers' quality of life. There is also a question of whether psychosocial interventions for carers that explore issues related to choice and reasons for caring (…) for example, in being supported to explore, articulate, and reframe their reasons for caring alongside the potential to explore and implement adjustments to the amount or type of care-giving (…) may improve carers' quality of life.

5 | CONCLUSION

This study has shown that reasons for caring are associated with carer care-related quality of life, as well as strain. The findings indicate that reasons for caring are related to carers' outcomes for carers of adults who use publicly-funded long-term care services. This is relevant to long-term care policy and practice, like that in England, that seeks to be outcomes-based and to improve carers' well-being and quality of life through long-term care support (Department of Health, 2017; NHS England, 2016). While the carers' policy strategy in England has focussed on various carer-specific issues over the past two decades (Department of Health, 2010, 2014; NHS England, 2016), the issue of choice in terms of the decision of whether or not to provide care remains underdeveloped. This is partly attributable to the conflation of the needs of carers and care-recipients into a single unit to avoid complexity (Arksey & Glendinning, 2007). This issue has been addressed by developments in policy to recognise carers as individuals whose needs should be considered on an equal footing to the care-recipient (Department of Health, 2010, 2014; NHS England, 2016). However, it does not adequately recognise the potential tensions between carers and care-recipients' needs and outcomes: for example, if the carer feels constrained by the care-recipients' needs in their reason to provide care ('s/he wouldn't want anyone else'). Although there is a requirement to acknowledge carers' choice in whether to provide care (NHS England, 2016), the long-term care system in England, like in many other countries, depends on informal care. This study, however, highlights that this dependency on informal care may have an adverse effect on carers' wellbeing if carers are under pressure to provide care. A more nuanced understanding of these tensions may further the broad aim of improving quality of life of care-recipients and their carers.

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