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# Why do they care? A qualitative systematic review and meta-synthesis of personal and relational motivations for providing informal care

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## ABSTRACT

Informal caregiving is crucial to the sustainability of health and social care systems globally. With ageing populations and a rising prevalence of acute and chronic health conditions, the need for informal care is growing, making it important to understand what motivates individuals to care and to continue caring. This paper reports findings of a systematic review which examined determinants of motivations and willingness to provide informal care. A systematic search was conducted using six electronic databases and a wide range of additional sources. 105 qualitative studies published before August 2019 were included with 103 of them reporting on personal and relational motivations, and the contextual factors underpinning these. Grounded theory-based, thematic synthesis was applied to synthesise the literature. This meta-synthesis reports on findings from across the world spanning three decades, with data from over 2500 caregivers across a range of health conditions. This paper presents the relational, personal and contextual themes. It highlights the significance of reciprocity, affection, family values and caregiving obligations. Personal characteristics, finding meaning, illness perceptions, situational and temporal aspects of caregiving are also identified as important in shaping motivations and willingness to care and to continue caring. Implications for theory, research, policy and practice are discussed.

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## KEYWORDS

Informal caregiving; motivations and willingness to provide care; personal characteristics; illness perceptions; relationship quality; reciprocity

## Introduction

Demographic and social trends, including the ageing population, smaller average family size, greater geographic and social mobility, and changing gender roles due in part to more women working outside the home, shape the demand for informal care (Albertini et al., 2007; Erickson, 2002; Stajduhar et al., 2010). Informal caregiving is the provision of usually unpaid care to a relative or friend with a chronic illness, disability, or other long-lasting health and care needs (Revenson et al., 2016). Definitions do vary across studies and within official recording systems of different countries, legislative, policy and practice contexts (Albertini et al., 2007; Erickson, 2002; Franco et al., 2002; Revenson et al., 2016; Stajduhar et al., 2010). Informal caregiving makes a significant contribution to the sustainability of health and social care systems (Albertini

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et al., 2007; Erickson, 2002; Stajduhar et al., 2010), hence, supporting and sustaining informal caregiving presents a considerable global challenge. Current understanding of the factors that underly, promote and maintain various motivations and willingness to provide informal care is limited (Deci et al., 2001; Lyonette & Yardley, 2003; Quinn et al., 2012). However, understanding motivations and willingness to provide care has implications for caregivers' and care recipients' well-being (e.g., Feeney & Collins, 2003; Quinn et al., 2012) as well as for assessment and care planning processes necessary to support caregiving relationships. This understanding also has implications for wider society – enhancing positive caregiving motivations, whilst not making assumptions about willingness to care, is increasingly important given the ageing demographic, societal expectations of community based, familial care provision and the potential costs to society of alternative care and support arrangements. It is important to understand what factors motivate the decision to provide care for someone and the factors that uphold the motivations over time.

Motivation is central to many psychological studies of behaviour (Cerasoli et al., 2014; Fisher et al., 2003; Franco et al., 2002; Hidi & Harackiewicz, 2000; Ryan & Deci, 2000), including caregiving, where caregiving motivation is defined as the meanings that direct particular caregiving-related actions (Dilworth-Anderson et al., 2005; Feeney & Collins, 2001; Ryan & Deci, 2000). Caregiving motivations may vary in terms of intensity and type, with some people being more or less motivated to provide care than others (Deci et al., 2001; Ryan & Deci, 2000). The most frequently used categorisation of caregiving motivations distinguishes between intrinsic and extrinsic motives (e.g., Feeney & Collins, 2003; Lyonette & Yardley, 2003; Quinn et al., 2012). Intrinsic motivations are shaped by an inherent, internalised drive to provide care, and extrinsic motivations are shaped by perceived external pressures and social values (Quinn et al., 2012; Romero-Moreno et al., 2017; Ryan & Deci, 2000).

Feeney and Collins (2003) conceptualised motivations for caregiving as altruistic and egoistic. Love and concern were identified as altruistic motivations, while caregiver enjoyment of helping was altruistic and egoistic. Other egoistic motivations included: a self-belief in caring competence, caregiving as a way of obtaining the care recipient's commitment and achieving relationship stability, feeling obliged and expectations of self-benefit. Their findings confirmed that caregiving motivations were associated with characteristics of the caregiver and the caregiving relationship. Caregivers with low self-esteem, depression, an insecure attachment style and an unsupportive relationship history with the care recipient described egoistic motivations. Caregivers with high levels of within relationship satisfaction and trust described altruistic motivations for caring. Caregiving motives were associated with caregiving behaviours (e.g., responsive, overinvolved, and controlling caregiving). Similarly, Wallroth (2016) highlighted the importance of relationship quality in shaping motivations to provide care.

Alongside the concept of motivations to provide care, there is also willingness to provide care which emphasises the behavioural aspects of caregiving with current and future attitudes towards providing particular kinds of support for someone (Abell, 2001; Zarzycki & Morrison, 2021). Thus, motivations refer broadly to the reasons underlying, directing and maintaining caregiving behaviours (Ryan & Deci, 2000; Woolfolk, 2013), whilst willingness to perform care addresses specific aspects of caregiver behaviour, for example willingness to carry out particular emotional, personal or practical care tasks (Abell, 2001; McDonnell et al., 1991). An individual may have various motivations to provide (or not to provide) care for someone, but simultaneously or subsequently they may not be willing to carry out particular caring tasks (e.g., intimate personal care tasks) (Zarzycki & Morrison, 2021).

Quinn et al. (2010) in their quantitative systematic review synthesised 4 studies looking at the impact of motivations on dementia caregiver outcomes, laying the ground for future studies to explore the significance caregiver motivations bear for caregiver wellbeing across other conditions. Burrige et al. (2007) in their mixed-method systematic review of 17 studies exploring reluctance to provide care and focusing mainly on cancer caregiving identified 4 groups of

willingness to care indicators (demographic, physical, social and psychological – including emotions). They provided the first synthesis of evidence pertaining to the role willingness to provide care plays in informal care.

To date, no review has synthesised qualitative evidence on motivations and willingness to provide informal care, hence there is limited insight into the experiential aspects of decision-making processes and the motivators responsible for continuation (or discontinuation) of the role.

### **Review aims**

The main review objectives were as follows:

- (a) Identify, describe, and critically appraise the literature on determinants of motivations and willingness to provide care.
- (b) Explore and synthesise the factors underlying caregivers' motivations and willingness to provide care.
- (c) Identify implications for theory development, future research, policy, and practice.

### **Methods**

#### **Protocol registration**

A systematic review protocol was registered by the Centre for Reviews and Dissemination – National Institute for Health Research at the University of York (available from: [https://www.crd.york.ac.uk/prospero/display\\_record.php?RecordID=149458](https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=149458)).

#### **Design**

Following EPPI centre guidance (Centre E for P and PI and C, 2010; Gough et al., 2017) this review presents the findings of a configurative qualitative systematic review and meta-synthesis, with a focus on relational, personal and contextual influences (i.e., 'micro', individualistic determinants) on motivations and willingness to provide care. This paper integrates results of qualitative studies with interpretive rather than aggregative intent (Booth, 2016). A separate paper (Zarzycki et al., 2022) presents a synthesis of qualitative findings relating to 'macro' (cultural and societal) influences on motivations and willingness to provide care, which are qualitatively different in scope, nature and underpinning theory.

#### **Eligibility criteria**

*Population:* Adult (aged 18 years and over) informal caregivers self-identified as the primary caregiver.

*Phenomena of interest (Concepts):* Studies exploring motivations and willingness to provide care.

*Design:* Qualitative studies and mixed methods studies where qualitative data could be separated from quantitative data.

*Study type:* Empirical qualitative research. There were no restrictions on settings or date. Studies reported in English, French, Polish or Russian languages were included. No restrictions were applied to caregiver relationship type (e.g., spouse/non spouse), caregiver gender, care recipient's age, care recipient gender or care recipient diagnosis.

*Exclusion criteria:* no empirical data pertaining to any of the key concepts.

The detailed selection criteria are specified in the Title and Abstract Screening Tools (see online S1 Supplementary File).

## **Identification of studies**

### **Search strategy**

A preliminary search was undertaken applying free text terms and thesaurus terms partially used by a previous systematic review of the impact of motivations on caregiver outcomes (Quinn et al., 2010) as well as scoping searches.

### **Information sources**

The systematic literature search examined papers published up to and including August 2019. The following databases were searched: MEDLINE via EBSCO, PsychInfo, Applied Social Sciences Index and Abstracts, CINAHL, Cochrane Library, Web of Science.

The search terms applied were:

- motivation, 'motivations to care', 'motivations to provide care', motive\*, drive, oblig\*, duty, filial,
- 'willingness to care', 'willingness to provide care', willing\*,
- value\*, 'familism', social, personal, ethnic\*, cultural, demographic\*, diagnosis, illness, characteristic\*, determinant\*,
- caregiver\*, spouse, partner, family, relative\*, carer\*, caregiving.

Data management was supported by RefWorks (Centre E for P and PI and C, 2010). Duplicates were removed before reviewing against the eligibility criteria.

A trawl of additional sources was conducted to ensure that the search was comprehensive and publication bias minimised.

### **Selection process**

Titles and abstracts of identified texts from scientific databases and additional literature sources were firstly screened by the principal researcher (MZ). Retrieval and review of potentially eligible full-text papers were then conducted by two reviewers (MZ, EB) with dual review of a sample of 20% to ensure consistent application of eligibility criteria and appropriate classification of studies.

### **Data extraction**

Qualitative and mixed-method data extraction forms were applied based on guidance published by Cochrane, the Joanna Briggs Institute and the EPPI Centre (Centre E for P and PI and C, 2010; Gough et al., 2017; Institute, 2015; Noyes & Lewin, 2011). Standardised and comprehensive data extraction forms for eligible studies designed for the purposes of the descriptive map and synthesis were completed for each study that met the inclusion criteria, i.e., information on the country of study; study aims relevant to this review; participants' characteristics; research methods; main constructs from the conceptual framework (the content of the interview guide) were extracted. The data extraction process was independently checked for accuracy by the second reviewer employing double coding on 20% of the included studies. There were no substantial differences in the way the qualitative studies were coded. Single coding proceeded on the remaining studies as a 100% rate of agreement was achieved (Gough et al., 2017).

### **Quality and relevance appraisal (QRA)**

Quality and relevance appraisals (QRA) were conducted using quality assessment tools by two researchers (MZ, EB) on 20% of the included studies. The inter-rater reliability was conducted and quantified using Kappa scores and single critical appraisal followed on the remaining studies as a

high rate of agreement was achieved. Each reviewer scored 200 items and agreed in 188 cases (94%). Inter-rater reliability was substantial ( $\kappa = .70$ ).

Each study was assessed according to the three '*Dimensions of Difference*' of Evidence Claims (Gough et al., 2017). The three dimensions were appraised as follows:

- (1) *the review methods* – methodological standard was assessed using the PRISMA statement (see online S1 Supplementary File) for the appropriateness of the review methods to limit reporter bias.
- (2) *the methods of the included studies* were assessed with the Weight of Evidence Framework (Gough et al., 2017) which critically appraised three aspects including: methodological standards ('soundness' of the study), suitability and relevance. The soundness of studies was assessed using the 10-item Critical Appraisal Skills Programme (CASP) tool (see online S1 Supplementary File for CASP qualitative checklist for the meta-synthesis demonstrating how each study addressed the CASP qualitative checklist quality aspects; (CASP, 2014)). The appropriateness of the methodology to answer the systematic review research questions and the relevance of the individual study to the review, were judged in accordance with the review aims and awarded an assessment of high, medium, or low (see online S1 Supplementary File).
- (3) The quality of *the evidence produced* was assessed using the GRADE-CERQual approach (Lewin et al., 2018). The GRADE-CERQual Qualitative Evidence Profile is presented in the Summary of Qualitative Findings table (Lewin et al., 2018) – see online S2 Supplementary File.

The lead reviewer (MZ) assessed confidence in each emerging analytic theme for specific study characteristics including study design, caregiver's gender and ethnicity, care recipient's illness, relationship between a caregiver and care recipient, geographic location and the socioeconomic level of development of the countries represented, employing the categories of developed and developing countries (List of Developing Countries, 2018).

Confidence in findings when removing 4 studies with low methodological quality was assessed using sensitivity analysis. A table is presented in online S2 Supplementary File that lists the analytic themes and descriptive subthemes by the selected study attributes. Assessment by study continent rather than country was explored due to the high number of included papers with sole countries. It was not possible to assess age and duration of care provision across each analytic theme as these characteristics were inadequately reported in some studies.

### **Data synthesis**

The review synthesis comprised of two stages. Systematic mapping of all identified studies and their characteristics was conducted using the EPPI-Centre core keywording strategy (EPPI-Centre SSRU, EPPI-Centre, 2002). Studies were coded according to demographic data and review-specific data before producing a descriptive map of all studies meeting the inclusion criteria. In-depth review was completed using *inductive grounded theory-based, thematic synthesis* to synthesise study findings and assess concepts across papers (Britten et al., 2002; Gough et al., 2017; Thomas & Harden, 2008), i.e., thematic synthesis was directed by the grounded-theory approach according to guidance (Qadir et al., 2013; Wallhagen & Yamamoto-Mitani, 2006; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019). Applying a grounded theory approach to synthesis deepened 'immersion' within the data through the application of selected analytic techniques (i.e., constant comparisons, coding principles, memoing in each stage of synthesis), thus adding additional depth and richness to the generation of the themes (e.g., further clarifying the definition and scope of each theme, detailing processes described within subthemes and analytic themes, enabling robust comparisons between the themes). The three main steps of the synthesis consisted of: (a) coding text as axial

codes; (b) organising the axial codes into ‘descriptive themes’; (c) generating ‘analytic themes’, i.e., themes ‘beyond’ the content of the primary studies that answer the review questions (Chamberlain et al., 2019; Gough et al., 2017).

Preliminary coding was supported by NVivo 12 Pro. Each axial code, descriptive theme and analytic theme was presented in a table with a summary of themes and the accompanying references – see online S2 Supplementary File.

During synthesis, exceptions were explored to see if they could be explained by attributes of the study population, e.g., gender, ethnicity, etc. After descriptive subthemes were generated and described an assessment of these in relation to preselected study characteristics was made – see online S2 Supplementary File.

## Findings

### Search results

The PRISMA diagram summarises the search flow (Figure 1). Electronic searches identified a total of 9793 papers. After duplicate removal ( $N = 4141$ ) the remaining 5652 articles were screened by title and abstract. Following exclusions ( $N = 5462$ ), 190 full-text records were assessed for eligibility. Final exclusions ( $N = 80$ ) resulted in 110 studies being included in the qualitative descriptive map and 105 in the qualitative data synthesis (five studies were ineligible for meta-synthesis). Figure 1 describes the main reasons for exclusion.

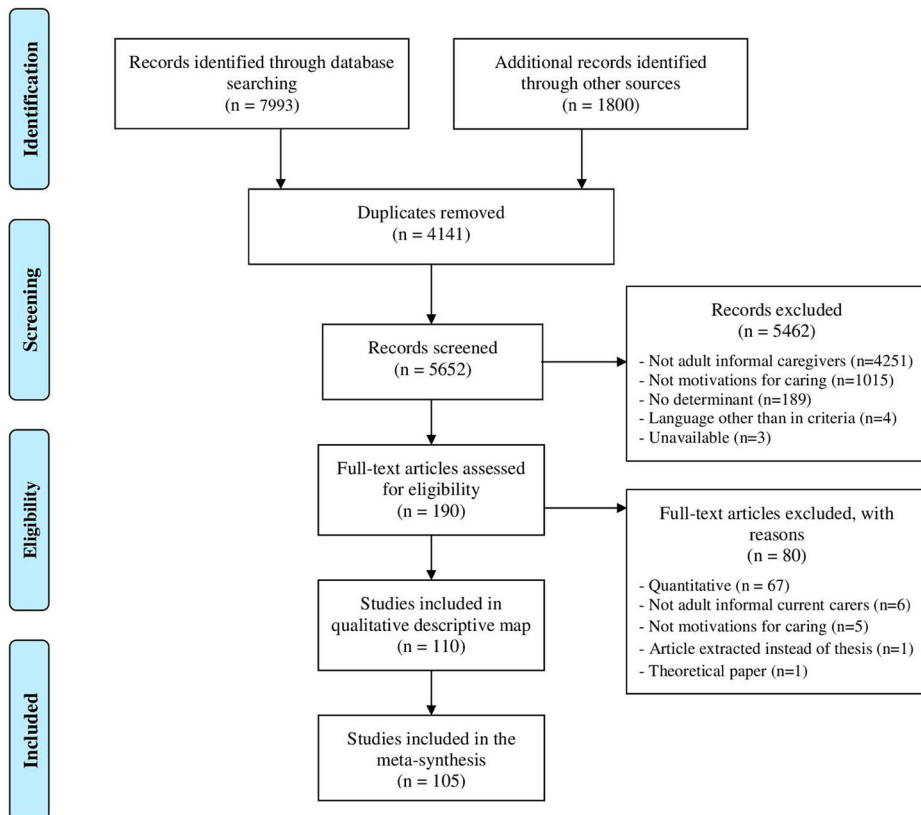


Figure 1. PRISMA flow chart of included studies.

### Characteristics of included studies

The characteristics of included studies are presented below and also summarised in table – see online S2 Supplementary File. The three analytic themes described in this paper are based on 103 studies of the 105 that were included in the overall review, i.e., 2 papers (Park, 2015; Qadir et al., 2013) did not provide data for the present synthesis (but contributed to themes described in a different paper).

*Setting:* All continents were represented: Asia ( $N = 23$ ) (Arpanantikul, 2018; Chao & Roth, 2000; Harris & Long, 1999; Holroyd, 2001; Holroyd, 2003; Holroyd, 2005; Hsu & Shyu, 2003; Kao & Stuijbergen, 1999; Kristanti et al., 2019; Kuşçu et al., 2009; Lee et al., 2019; Leichtentritt et al., 2004; Li et al., 2012; Mok et al., 2003; Ng et al., 2016; Pang & Lee, 2019; Park, 2015; Qadir et al., 2013; Qiu et al., 2018; Sung, 1994; Wallhagen & Yamamoto-Mitani, 2006; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019), Middle East ( $N = 3$ ) (Dumit et al., 2015; Kuşçu et al., 2009; Leichtentritt et al., 2004), Africa ( $N = 6$ ) (Gurayah, 2015; Knight et al., 2016; Kodwo-Nyameazea & Nguyen P, 2008; Mahilall, 2006; Muoghalu & Jegede, 2010; Van Sjaak Geest, 2002), Europe ( $N = 22$ ) (Albinsson & Strang, 2003; Bashir, 2014; Bäckström & Sundin, 2010; Boeije et al., 2003; Dunér, 2010; Foster, 2012; Lauritzen et al., 2019; Lin et al., 2012; McDonnell & Ryan, 2014; Öhman & Söderberg, 2004; Øydgard, 2017; Parveen et al., 2011; Quinn, 2009; Rivera et al., 2009; Sand et al., 2010; Sasat, 1998; Statham, 2003; Tretteteig et al., 2017a; Tretteteig et al., 2017b; Vellone et al., 2002; Wallroth, 2016; Williams et al., 2014), Australia and Oceania ( $N = 4$ ) (Bryant & Lim, 2013; Cahill, 1999; Cash et al., 2013; Opie, 1994); North America ( $N = 49$ ) (Erickson, 2002; Wallhagen & Yamamoto-Mitani, 2006; Han et al., 2008; Hinton et al., 2008; Ho et al., 2003; Hsueh et al., 2008; Jones et al., 2002; Kietzman et al., 2013; Kim & Theis, 2000; Kong et al., 2010; Mendez-Luck & Anthony, 2016; Meyer et al., 2015; Sung, 1994; Park, 2012; Sheu, 1997; Spitzer et al., 2003; Yeo et al., 2002; Anngela-Cole & Busch, 2011; Guberman et al., 1992; McDermott & Mendez-Luck, 2018; Murphy, 2005; Nkongho & Archbold, 1995; Sterritt & Pokorny, 1998; Dunér, 2010; Donorfio & Kellett, 2006; Hanyok et al., 2009; Harris, 1998; Kim, 2009; Strumpf et al., 2001; Aronson, 1992; Clark & Huttlinger, 1998; Merrill, 1996; Weinland, 2009; Wiles, 2002; Albinsson & Strang, 2003; Lewis et al., 1995; de Leon Arabit, 2005; Russell, 2001; Funk, 2012; Jones et al., 2003; Mars, 2015; Morgan & Laing, 1991; Neufeld & Harrison, 1998; Stajduhar et al., 2008; Gerdner et al., 2007; Cahill, 1999; Pierce, 2001; Alonso et al., 2018; Pelusi, 1999; Opie, 1994; Browne Sehy, 1998; Donovan & Williams, 2015; Gliberman, 1996), South America ( $N = 1$ ) (Almeida et al., 2018). Twenty studies were conducted in what is considered a developing country (Almeida et al., 2018; Arpanantikul, 2018; Dumit et al., 2015; Gurayah, 2015; Holroyd, 2001; Holroyd, 2003; Holroyd, 2005; Knight et al., 2016; Kodwo-Nyameazea & Nguyen P, 2008; Kristanti et al., 2019; Kuşçu et al., 2009; Li et al., 2012; Mahilall, 2006; Mok et al., 2003; Muoghalu & Jegede, 2010; Pang & Lee, 2019; Qadir et al., 2013; Qiu et al., 2018; Van Sjaak Geest, 2002; Zhang & Lee, 2019) and 3 studies (Harris & Long, 1999; Sung, 1994; Yamamoto & Wallhagen, 1997) were conducted on two different continents (e.g., USA and Japan).

*Participants:* 2565 caregivers participated in the included studies with 77% being female ( $N = 1986$ ) and 23% male ( $N = 579$ ).

*Caregiver age* ranged from 16 to 91 years approximately. However, in five studies age was indicated by the age of the youngest person, e.g., 23+ (Chao & Roth, 2000; Kim & Theis, 2000; Leichtentritt et al., 2004; Muoghalu & Jegede, 2010; Weinland, 2009) and three studies concerned older caregivers exclusively (age above 64 with no upper age limit specified) (Holroyd, 2005; Lin et al., 2012; Russell, 2001).

*Caregiver ethnicity* was reported in most (92, 88%) studies. In 13 studies (12%) the ethnicity was highly varied (Almeida et al., 2018; Anngela-Cole & Busch, 2011; Browne Sehy, 1998; Harris, 1998; Harris & Long, 1999; Kietzman et al., 2013; Murphy, 2005; Parveen et al., 2011; Pelusi, 1999; Strumpf et al., 2001; Sung, 1994; van Wezel et al., 2016; Wallhagen & Yamamoto-Mitani, 2006). In 79 (75%) studies ethnicity was divided into broad sub-categories: mostly Caucasian ethnicity ( $N = 25$ ) (Alonso et al., 2018; Aronson, 1992; Bäckström & Sundin, 2010; Donorfio & Kellett, 2006;



Dunér, 2010; Foster, 2012; Funk, 2012; Globerman, 1996; Guberman et al., 1992; Hanyok et al., 2009; Lauritzen et al., 2019; McDonnell & Ryan, 2014; Merrill, 1996; Öhman & Söderberg, 2004; Øydgard, 2017; Quinn, 2009; Rivera et al., 2009; Russell, 2001; Sand et al., 2010; Stajduhar et al., 2008; Tretteteig et al., 2017a; Tretteteig et al., 2017b; Vellone et al., 2002; Wallroth, 2016; Williams et al., 2014); Asian ethnicity ( $N=36$ ) (Wallroth, 2016; Qadir et al., 2013; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019; Holroyd, 2001; Hsu & Shyu, 2003; Kristanti et al., 2019; Pang & Lee, 2019; Holroyd, 2003; Li et al., 2012; Dumit et al., 2015; Sasat, 1998; Arpanantikul, 2018; Bashir, 2014; Lauritzen et al., 2019; Bäckström & Sundin, 2010; Dunér, 2010; McDonnell & Ryan, 2014; Sand et al., 2010; Foster, 2012; Öhman & Söderberg, 2004; Quinn, 2009; Tretteteig et al., 2017a; Chao & Roth, 2000; Williams et al., 2014; Bryant & Lim, 2013; Donovan & Williams, 2015; Han et al., 2008; Hinton et al., 2008; Ho et al., 2003; Hsueh et al., 2008; Jones et al., 2002; Kim & Theis, 2000; Kong et al., 2010; Holroyd, 2005; Meyer et al., 2015; Park, 2012; Sheu, 1997; Spitzer et al., 2003; Yeo et al., 2002; Guberman et al., 1992; Donorfio & Kellett, 2006; Kim, 2009; Merrill, 1996; Russell, 2001; Kao & Stuifbergen, 1999; Funk, 2012; Jones et al., 2003; Alonso et al., 2018; Lee et al., 2019; Mok et al., 2003; Ng et al., 2016; Qiu et al., 2018; Mendez-Luck & Anthony, 2016; McDermott & Mendez-Luck, 2018; Nkongho & Archbold, 1995; Sterritt & Pokorny, 1998; Clark & Huttlinger, 1998; Weinland, 2009; de Leon Arabit, 2005; Mars, 2015; Gerdner et al., 2007; Pierce, 2001); Black African ethnicity ( $N=6$ ) (Gurayah, 2015; Knight et al., 2016; Kodwo-Nyameazea & Nguyen P, 2008; Mahilall, 2006; Muoghalu & Jegede, 2010; Van Sjaak Geest, 2002); Arab ethnicity ( $N=2$ ) (Kuşçu et al., 2009; Leichtenritt et al., 2004). In a minority of studies ( $N=13$ , 12%) ethnicity was either not reported/inconsistently reported (11) or inapplicable (2 documentary studies) (Albinsson & Strang, 2003; Boeije et al., 2003; Cahill, 1999; Cash et al., 2013; Erickson, 2002; Lewis et al., 1995; Lin et al., 2012; Morgan & Laing, 1991; Neufeld & Harrison, 1998; Opie, 1994; Park, 2015; Statham, 2003; Wiles, 2002).

Six studies (6%) did not report the *type of caregiver-recipient relationship* (Anngela-Cole & Busch, 2011; Knight & Sayegh, 2010; Muoghalu & Jegede, 2010; Rivera et al., 2009; Strumpf et al., 2001; Van Sjaak Geest, 2002), most studies ( $N=63$ , 60%) included mixed categories of relatives; 24 studies (23%) were focused mostly (at least 90% of caregivers participating) on adult children (Alonso et al., 2018; Aronson, 1992; Bryant & Lim, 2013; Chao & Roth, 2000; Donorfio & Kellett, 2006; Erickson, 2002; Funk, 2012; Gerdner et al., 2007; Globerman, 1996; Harris, 1998; Holroyd, 2001; Hsueh et al., 2008; Jones et al., 2002; Jones et al., 2003; Kodwo-Nyameazea & Nguyen P, 2008; Kong et al., 2010; Lewis et al., 1995; McDonnell & Ryan, 2014; Merrill, 1996; Sheu, 1997; van Wezel et al., 2016; Wallhagen & Yamamoto-Mitani, 2006; Wallroth, 2016; Yamamoto & Wallhagen, 1997); 11 studies (10%) were with mainly (at least 90%) spousal/partner caregivers (Boeije et al., 2003; Browne Sehy, 1998; de Leon Arabit, 2005; Foster, 2012; Holroyd, 2005; Lin et al., 2012; Morgan & Laing, 1991; Öhman & Söderberg, 2004; Pang & Lee, 2019; Pelusi, 1999; Russell, 2001); one study (1%) concerned non-relative caregivers (Mahilall, 2006). After excluding studies in which relationship type was either not reported or unclear it was noted that most caregivers were adult children ( $N=1237$ , 61%), followed by spousal/partnership caregivers ( $N=540$ , 27%). The outstanding 12% ( $N=247$ ) of caregivers comprised other relatives providing informal care or non-relatives.

In 23 studies (22%) care recipient's health condition was not specified (Arpanantikul, 2018; Bashir, 2014; Bryant & Lim, 2013; Clark & Huttlinger, 1998; Donorfio & Kellett, 2006; Donovan & Williams, 2015; Dunér, 2010; Erickson, 2002; Funk, 2012; Hanyok et al., 2009; Hsu & Shyu, 2003; Hsueh et al., 2008; Jones et al., 2002; Jones et al., 2003; Kietzman et al., 2013; Kodwo-Nyameazea & Nguyen P, 2008; Lewis et al., 1995; Merrill, 1996; Statham, 2003; Sung, 1994; Van Sjaak Geest, 2002; Wallroth, 2016; Weinland, 2009) whilst 30 (28%) included various condition types within the study sample. Fifty-two (50%) studies included a single diagnosis: dementia ( $N=36$ , 34%) (Albinsson & Strang, 2003; Cahill, 1999; Foster, 2012; Gerdner et al., 2007; Globerman, 1996; Gurayah, 2015; Harris, 1998; Hinton et al., 2008; Ho et al., 2003; Kim, 2009; Kong et al., 2010; Lauritzen et al., 2019; Leichtenritt et al., 2004; Lin et al., 2012; Mars, 2015; McDonnell & Ryan, 2014; Meyer et al., 2015; Morgan & Laing, 1991; Murphy, 2005; Neufeld & Harrison, 1998; Opie, 1994; Øydgard, 2017; Pang & Lee, 2019; Qadir et al., 2013; Quinn, 2009; Rivera et al., 2009; Russell, 2001; Sasat, 1998; Sterritt &

Pokorny, 1998; Tretteteig et al., 2017a; Tretteteig et al., 2017b; van Wezel et al., 2016; Vellone et al., 2002; Wallhagen & Yamamoto-Mitani, 2006; Yamamoto & Wallhagen, 1997; Yeo et al., 2002), cancer ( $N = 7, 7\%$ ) (Anngela-Cole & Busch, 2011; Kristanti et al., 2019; Kuşçu et al., 2009; Mok et al., 2003; Ng et al., 2016; Pelusi, 1999; Stajduhar et al., 2008), cardiac diseases ( $N = 3, 3\%$ ) (Alonso et al., 2018; Dumit et al., 2015; Holroyd, 2003), strokes ( $N = 5, 5\%$ ) (Bäckström & Sundin, 2010; de Leon Arabit, 2005; Pierce, 2001; Qiu et al., 2018; Zhang & Lee, 2019) and multiple sclerosis ( $N = 1, 1\%$ ) (Boeije et al., 2003).

*Study design:* 96 (91%) of the 105 synthesised studies were qualitative in design with a further 9 mixed method studies containing qualitative data which was reported separately ( $N = 9, 9\%$ ) (Cahill, 1999; Kietzman et al., 2013; Kim & Theis, 2000; Merrill, 1996; Muoghalu & Jegede, 2010; Rivera et al., 2009; Sasat, 1998; Statham, 2003; Strumpf et al., 2001). Of these 16 (15%) employed a longitudinal study design (Alonso et al., 2018; Bashir, 2014; Browne Sehy, 1998; Donovan & Williams, 2015; Foster, 2012; Funk, 2012; Gerdner et al., 2007; Knight et al., 2016; Kong et al., 2010; Lin et al., 2012; Mahilall, 2006; Mars, 2015; Neufeld & Harrison, 1998; Opie, 1994; Statham, 2003; Wallhagen & Yamamoto-Mitani, 2006).

*Critical appraisal of the methodological quality of studies:* The majority of the 105 studies were judged to be of high methodological quality – 57 (54%) had no or very minor methodological concerns (Wallroth, 2016; Arpanantikul, 2018; Kristanti et al., 2019; Pang & Lee, 2019; Li et al., 2012; Leichtentritt et al., 2004; Dumit et al., 2015; Kodwo-Nyameazea & Nguyen P, 2008; Mahilall, 2006; Parveen et al., 2011; Lauritzen et al., 2019; Bäckström & Sundin, 2010; Chao & Roth, 2000; McDonnell & Ryan, 2014; Boeije et al., 2003; Statham, 2003; Albinsson & Strang, 2003; Lin et al., 2012; Sand et al., 2010; Foster, 2012; Öhman & Söderberg, 2004; Tretteteig et al., 2017a; Williams et al., 2014; Holroyd, 2005; Tretteteig et al., 2017b; Bryant & Lim, 2013; Browne Sehy, 1998; Donovan & Williams, 2015; Gliberman, 1996; Han et al., 2008; Ho et al., 2003; Hsueh et al., 2008; Jones et al., 2002; Kietzman et al., 2013; Lee et al., 2019; Kong et al., 2010; Meyer et al., 2015; Sheu, 1997; McDermott & Mendez-Luck, 2018; Murphy, 2005; Donorfio & Kellett, 2006; Harris, 1998; Kim, 2009; Clark & Huttlinger, 1998; Weinland, 2009; Mok et al., 2003; de Leon Arabit, 2005; Jones et al., 2003; Neufeld & Harrison, 1998; Gerdner et al., 2007; Pierce, 2001; Alonso et al., 2018; Almeida et al., 2018; Ng et al., 2016; Qiu et al., 2018; Zhang & Lee, 2019; Hsu & Shyu, 2003), 44 (42%) were judged to be moderate (Anngela-Cole & Busch, 2011; Bashir, 2014; Cahill, 1999; Cash et al., 2013; Dunér, 2010; Erickson, 2002; Funk, 2012; Guberman et al., 1992; Gurayah, 2015; Harris & Long, 1999; Hinton et al., 2008; Holroyd, 2001; Kao & Stuijbergen, 1999; Kim & Theis, 2000; Knight et al., 2016; Kuşçu et al., 2009; Lewis et al., 1995; Mars, 2015; Mendez-Luck & Anthony, 2016; Merrill, 1996; Morgan & Laing, 1991; Muoghalu & Jegede, 2010; Nkongho & Archbold, 1995; Opie, 1994; Øydgard, 2017; Park, 2012; Park, 2015; Pelusi, 1999; Qadir et al., 2013; Quinn, 2009; Rivera et al., 2009; Russell, 2001; Sasat, 1998; Spitzer et al., 2003; Stajduhar et al., 2008; Sterritt & Pokorny, 1998; Strumpf et al., 2001; Van Sjaak Geest, 2002; van Wezel et al., 2016; Vellone et al., 2002; Wallhagen & Yamamoto-Mitani, 2006; Wiles, 2002; Yamamoto & Wallhagen, 1997; Yeo et al., 2002), and 4 studies (Aronson, 1992; Hanyok et al., 2009; Holroyd, 2003; Sung, 1994), which met the requirements for the data synthesis and were thus retained, were judged to be of low quality. The remaining 5 studies (Asahara et al., 2002; Kellett, 1999; McDonnell et al., 1991; Piotrowska, 2015; Takigiku et al., 1993) judged to be of low quality bore limitations in synthesis/analysis of data, data adequacy, clear statement of the findings and were not included in the synthesis. The summary critical appraisal assessment of overall methodological quality for each study is provided in online S2 Supplementary File.

### **Meta-synthesis of study findings**

Diverse determinants of motivations and willingness to provide care were identified in the reviewed studies with five broad analytic themes identified following grounded theory analysis and thematic synthesis. The current paper describes three themes pertaining to individualistic influences on caregiving motivations and willingness:

Contextual aspects of caregiving  
 The nature of relationship/relational aspects  
 Personal characteristics, beliefs and resources

Confidence in each of the analytic themes is based on the GRADE CERQual assessment summarised in online S2 Supplementary File. Removing studies with low methodological quality did not influence confidence in findings (assessed during sensitivity analysis). Given the high number of qualitative articles included in the synthesis ( $N = 103$ ), the contribution of studies with low methodological quality ( $N = 4$ , 4% of all included studies only) to any subtheme did not influence confidence in findings, as it were the studies with high – and moderate–methodological quality ( $N = 99$ ) that provided most evidence to the findings. The four low-quality studies did not comprise any stand-alone subtheme, i.e., they did not bias the findings as reported. However, there are minor or moderate concerns regarding data adequacy and relevance when considering available data from some subpopulations and continents, which reduced confidence in some findings (i.e., for male caregivers; caregivers with Black African and Arab ethnic origins; Australia and Oceania, South America and Middle East; and reported illness – other than dementia).

The three analytic themes are described, and subthemes highlighted in bold (see Figure 2 for the diagram of individualistic influences on caregiving motivations and willingness). Table 1 presents a selection of illustrative quotes for each subtheme. Summary overinclusive supporting quotes are provided in an extended version of the findings in online S2 Supplementary File.

### Theme 1: contextual aspects of caregiving

This theme highlights the importance of the wider situational and temporal context within which caregiving is situated. The contextual subthemes (1.1 and 1.2 below) affect the extent to which

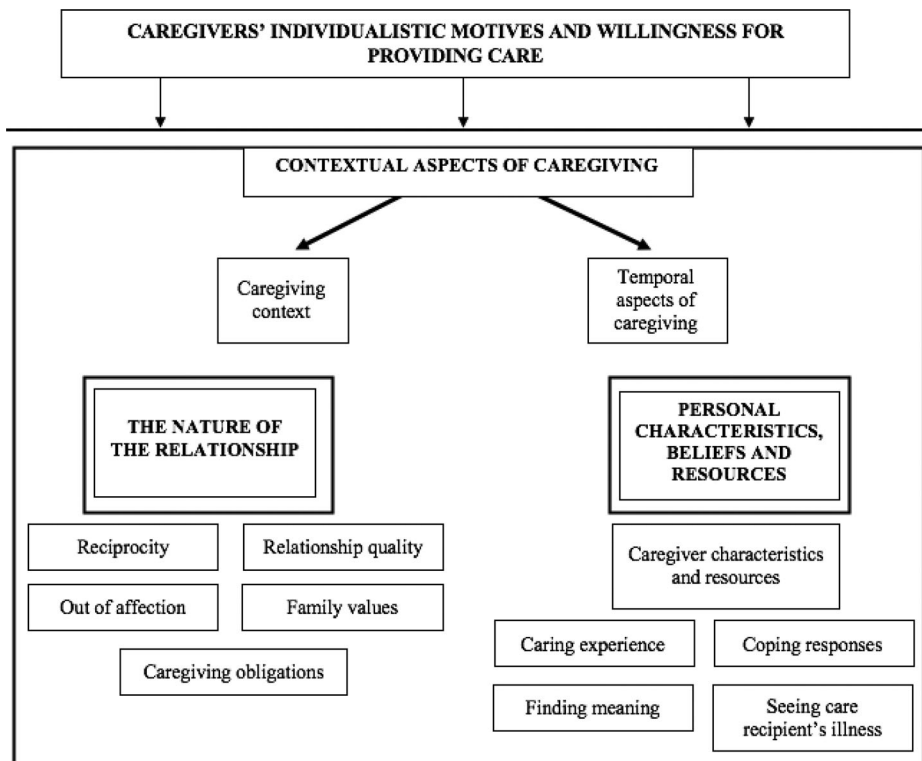


Figure 2. Diagram of individualistic influences on caregiving motivations and willingness.

**Table 1.** A selection of illustrative quotes for subthemes presented.

Analytic theme	Descriptive subtheme		Illustrative quote
1. Contextual aspects of caregiving	1.1 Caregiving context	1.1.1 Convenience factors	'It just naturally fell on the ones that are closest to the [elders] home'. (Erickson, 2002, p. 105) 'I'm her slave, a slave of [financial] circumstances ...'. (Guberman et al., 1992, p. 612)
		1.1.2 Competing priorities and demands	'Every day, I struggle with two choices: to work and let my dad go to the hospital alone, or to accompany him and have no money to pay the bills'. (Ng et al., 2016, p. 1303)
	1.2 Temporal aspects of caregiving		'So, at first, caregiving was a challenge and I didn't find it hard to do. After some years, there is wear and tear and the challenge is gone'. (Boeije et al., 2003, p. 247)
	2. The nature of the relationship	2.1 Reciprocity	2.1.1 Retrospective reciprocity
2.1.2 Expected reciprocity			'I love my parents very much and hopefully by caring for them I will get care back from my kids as an aging person'. (Donorfio & Kellett, 2006, p. 162)
2.2 Out of affection			'Because I love them, that's what makes me do what I do'. (Guberman et al., 1992, p. 609)
2.3 Relationship quality			'It makes me angry I have to consider him so much when he never considered me'. (Morgan & Laing, 1991, p. 382) 'You know, she always says 'thank you for being here!' Or she goes, 'I appreciate everything that you do!' So whatever bad things happen ... she'll tell me that and all bad things go away!' (Murphy, 2005, p. 87)
		2.4 Family values	
2.5 Obligations to provide care			'I am taking care of my mother because she is my mother. Who else can do this? This is my obligation'. (Strumpf et al., 2001, p. 243)
3. Personal characteristics, beliefs and resources	3.1 Caregiver's personal characteristics and resources		'... one isn't taught that, my girl, that [ability] comes from your heart, you will never learn that, I tell you that from experience and from my 66 years, no one will teach you to care for [or] love people, [it's up to] you alone'. (McDermott & Mendez-Luck, 2018, p. 6)
	3.2 Caregiving experience and expertise		'It's important to be competent in nursing. I'm sure it is much harder for an untrained person to take care of an elderly. I know the body's mechanics'. (Kim, 2009, p. 607)
	3.3 Coping responses		'You've got to do a lot of praying. It's the only thing that keeps me strong ... to help take care of her'. (Gerdner et al., 2007, p. 365)
	3.4 Finding meaning		'After being in this for a while, you start thinking what is the purpose [in life], and maybe the purpose is giving instead of getting. And so you give in some small way to somebody else who's important to you'. (Harris, 1998, p. 348)
	3.5 Seeing care recipient's illness		'But gradually, I began to feel, "Oh, well, this must be a law of nature [shizen no setsuri; laugh]." You know, like dying tree gradually changes, her body (also changes), you know, she is 89. I have come to feel that it cannot be helped [shikatanai], that gradually many functions deteriorate over time'. (Wallhagen & Yamamoto-Mitani, 2006, p. 69)

the other two themes pertaining the nature of relationships and personal characteristics, beliefs and resources are salient in terms of shaping caregiver motivations and willingness to provide care.

**1.1 Caregiving context.** This subtheme provides evidence on situational factors that underpin caregiver motivations and willingness, i.e., convenience factors, and competing priorities and demands that caregivers experience.

*Convenience factors* are those which make the caring role possible or necessary, for example: being the only child; being single; having flexibility to accommodate caregiving with existing employment commitments; not having young children, geographical proximity, having the material space or personal and financial means to provide care. The role of (a) geographical proximity; (b) the caregiver's own situation (e.g., physical space; (c) family structure (Anngela-Cole & Busch, 2011; Aronson, 1992; Bashir, 2014; Erickson, 2002; Guberman et al., 1992; Holroyd, 2001; Jones et al., 2002; Kietzman et al., 2013; Kuşçu et al., 2009; Merrill, 1996; Ng et al., 2016; Sasat, 1998; Strumpf et al., 2001; Wallroth, 2016; Wiles, 2002; Yamamoto & Wallhagen, 1997)); and (d) the dependence on the care recipient (Donorfio & Kellett, 2006; Guberman et al., 1992; Murphy, 2005; Parveen et al., 2011) were evident in caregiver accounts.

- (a) The distance to the care recipient – geographical proximity – shapes the way that people can provide care, with some caregivers expressing that living close to the care recipient may have shaped their motivation to care (Anngela-Cole & Busch, 2011; Erickson, 2002; Merrill, 1996; Wallroth, 2016; Wiles, 2002).
- (b) Aspects of the caregiver's own situation – available space, financial and personal means, their own situation (e.g., retired/ unemployed, having no competing caring or employment responsibilities) (Anngela-Cole & Busch, 2011; Bashir, 2014; Guberman et al., 1992; Kuşçu et al., 2009; Ng et al., 2016; Sasat, 1998; Strumpf et al., 2001).
- (c) Absence of siblings or other family members also determined motivations and willingness to provide care (Aronson, 1992; Jones et al., 2002; Kietzman et al., 2013; Wallroth, 2016; Yamamoto & Wallhagen, 1997) which relates to perceived choice in undertaking informal caregiving duties, described later (see subtheme 2.4).
- (d) Dependence on the care recipient refers to socioeconomic reliance on the care recipient, for example, some caregivers were financially dependent on the care recipient or reliant upon inheriting the care recipient's assets in the future. These types of factors are linked to extrinsic motivations in providing care (Donorfio & Kellett, 2006; Guberman et al., 1992; Murphy, 2005; Parveen et al., 2011).

*Competing priorities* and demands were described as the difficulties encountered when combining care responsibilities with employment; or competing familial roles (Alonso et al., 2018; Arpanantikul, 2018; Bryant & Lim, 2013; Kao & Stuifbergen, 1999; Ng et al., 2016; Spitzer et al., 2003). Adults caring for a parent(s) often reported a conflict between the responsibility for their parent and their nuclear family (sandwich generation) and/or employment; spouse caregivers reported balancing their own physical and psychological needs with their care recipient's needs (Albinsson & Strang, 2003; Alonso et al., 2018; Han et al., 2008; Ho et al., 2003; Jones et al., 2002; Jones et al., 2003; Kao & Stuifbergen, 1999; Kim & Theis, 2000; Knight et al., 2016; Li et al., 2012; Sheu, 1997; Spitzer et al., 2003; Weinland, 2009). Having paid employment constrained motivations to care and comprised a source of tension, heightened if the sociocultural context imposed expectations of caregiving (e.g., filial piety – described later) (Alonso et al., 2018; Arpanantikul, 2018; Bryant & Lim, 2013; Kao & Stuifbergen, 1999; Ng et al., 2016; Spitzer et al., 2003). Moreover, the competing demands associated with multiple roles increased burden and negatively influenced caregiver motivations and willingness to provide care (Albinsson & Strang, 2003; Alonso et al., 2018; Han et al., 2008; Ho et al., 2003; Jones et al., 2002; Jones et al., 2003; Kao & Stuifbergen, 1999; Kim & Theis, 2000; Knight et al., 2016;

Li et al., 2012; Sheu, 1997; Spitzer et al., 2003; Weinland, 2009), especially for the 'sandwich generation' of caregivers.

**1.2 Temporal aspects of caregiving.** The temporal orientation of caregiver motivations highlights how different motivational factors may be present at different points in time subject to changes in the care recipient's symptoms, care needs or caregiver's circumstances (e.g., the caregiver's health) (Alonso et al., 2018; Boeije et al., 2003; Browne Sehy, 1998; Foster, 2012; Ho et al., 2003; Hsu & Shyu, 2003; Kong et al., 2010; Lin et al., 2012; Opie, 1994; Parveen et al., 2011; Quinn, 2009; Sasat, 1998; Stajduhar et al., 2008; Williams et al., 2014). However, only 16 studies (Alonso et al., 2018; Bashir, 2014; Browne Sehy, 1998; Donovan & Williams, 2015; Foster, 2012; Funk, 2012; Gerdner et al., 2007; Knight et al., 2016; Kong et al., 2010; Lin et al., 2012; Mahilall, 2006; Mars, 2015; Neufeld & Harrison, 1998; Opie, 1994; Statham, 2003; Wallhagen & Yamamoto-Mitani, 2006) included in the review reported longitudinal prospective data and some others (Boeije et al., 2003; Browne Sehy, 1998; Ho et al., 2003; Hsu & Shyu, 2003; Kong et al., 2010; Parveen et al., 2011; Quinn, 2009; Sasat, 1998; Stajduhar et al., 2008; Williams et al., 2014) also relied on retrospective accounts of change.

Evidence of different factors influencing motivations to provide care at different stages of a 'caregiving career' (or 'caregiver journey'), is exemplified in Hsu and Shyu's (Hsu & Shyu, 2003) study of social exchanges amongst caregivers in Taiwan. Their findings showed that caregiver motivations changed over time from retrospective reciprocity motives (see subtheme 2.1), through expected reciprocity (see subtheme 2.2) and ending with being motivated by the pressure of social expectations when caregiving demands were higher.

Some caregivers described a prior or anticipated shift from love and responsibility motives to those related to seeking relief from care obligations and burden (i.e., relinquishing the caring role/finding alternative care arrangements). Some caregivers anticipated change due to foreseeing a likely deterioration in their care recipient's health condition, with some stating preparedness to care until the point where alternative arrangements, such as nursing care, were required (Browne Sehy, 1998; Foster, 2012). Not all caregivers considered that the role inevitably became more demanding (regardless of any decline, stabilisation or improvement in the care recipient's illness), with some considering that their role became easier due to the care duties becoming habitual routines, or perhaps by developing their caring skills with experience (Parveen et al., 2011).

Overall, the review evidence supports the presence of temporal shifts in motivations and willingness to provide care. Neither stability of motivation and willingness, nor adaptation over time, is inevitable given the often unpredictable nature of care and its associated demands (Boeije et al., 2003; Browne Sehy, 1998; Foster, 2012; Hsu & Shyu, 2003; Lin et al., 2012; Opie, 1994; Parveen et al., 2011; Williams et al., 2014).

## **Theme 2: the nature of the relationship**

This theme incorporates five descriptive subthemes: reciprocity; out of affection; relationship quality; family values; obligations to provide care.

**2.1 Reciprocity.** We distinguish between two different types of reciprocity present in the reviewed evidence with regards to the timeline of this caregiving motivation, i.e., *retrospective reciprocity* that refers to the reciprocation of the past 'debt' (e.g., to a parent); and subsequently to *expected reciprocity* that describes caregiving investment with regards to a caregiver's own children or other designated people (e.g., a spouse) in maintaining or establishing future support.

*Retrospective reciprocity* describes the reciprocation of a past 'debt' as a motivator to care and was a key determinant of motivation and willingness to provide care (Aronson, 1992; Browne Sehy, 1998; Bryant & Lim, 2013; Cahill, 1999; Chappell & Funk, 2012; Clark & Huttlinger, 1998; Donorfio & Kellett, 2006; Donovan & Williams, 2015; Dunér, 2010; Erickson, 2002; Guberman et al., 1992; Hanyok et al., 2009; Harris, 1998; Harris & Long, 1999; Holroyd, 2003; Holroyd, 2005; Hsu & Shyu, 2003; Jones et al., 2003; Kong et al., 2010; Mars, 2015; McDonnell & Ryan, 2014; Mendez-Luck & Anthony, 2016;

Ng et al., 2016; Nkongho & Archbold, 1995; Pang & Lee, 2019; Rivera et al., 2009; Russell, 2001; Sasat, 1998; Statham, 2003; Sung, 1994; van Wezel et al., 2016; Wallhagen & Yamamoto-Mitani, 2006; Wallroth, 2016; Wiles, 2002; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019). Retrospective reciprocity was described using terms such as 'giving back', 'paying back', 'repaying family', etc. (Albinsson & Strang, 2003; Almeida et al., 2018; Arpanantikul, 2018; Browne Sehy, 1998; Han et al., 2008; Harris, 1998; Hsueh et al., 2008; Jones et al., 2002; Kuşçu et al., 2009; Lee et al., 2019; Mahilall, 2006; McDermott & Mendez-Luck, 2018; Mok et al., 2003; Murphy, 2005; Qiu et al., 2018; Russell, 2001; Sand et al., 2010; Sheu, 1997; Statham, 2003; Strumpf et al., 2001; Wallroth, 2016) and it was seen in various forms: delayed reciprocity; hypothetical reciprocity; spousal reciprocity; constructed reciprocity; waived reciprocity; and direct reciprocity, each of which are illustrated below.

Delayed reciprocity was a perceived imperative to repay past 'investment' and sacrifice, i.e., a perceived debt, and was often identified as motivating the provision of care to parents (Aronson, 1992; Browne Sehy, 1998; Bryant & Lim, 2013; Cahill, 1999; Chappell & Funk, 2012; Clark & Huttlinger, 1998; Donorfio & Kellett, 2006; Donovan & Williams, 2015; Dunér, 2010; Erickson, 2002; Funk, 2012; Guberman et al., 1992; Hanyok et al., 2009; Harris, 1998; Harris & Long, 1999; Holroyd, 2003; Holroyd, 2005; Hsu & Shyu, 2003; Jones et al., 2003; Kong et al., 2010; Mars, 2015; McDonnell & Ryan, 2014; Mendez-Luck & Anthony, 2016; Ng et al., 2016; Nkongho & Archbold, 1995; Pang & Lee, 2019; Rivera et al., 2009; Russell, 2001; Sasat, 1998; Statham, 2003; Sung, 1994; van Wezel et al., 2016; Wallhagen & Yamamoto-Mitani, 2006; Wallroth, 2016; Wiles, 2002; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019).

Hypothetical reciprocity (also called *virtual and in-principle reciprocity* in the literature) maintained that the care recipient 'would' help the caregiver if the situation was reversed; often based on the shared understanding of the pre-existing caregiving relationship and an assumed reciprocity (Boeije et al., 2003; Harris & Long, 1999; Kim, 2009; Lin et al., 2012; Wiles, 2002). This was more characteristic of spousal/partner relationships and was crucial for many in terms of shaping their initial motivations for caring.

Spousal reciprocity was related to delayed reciprocity but with respect to spousal, not parental, 'debt'. It was reflected in terms of a care recipient having previously taken care for the spousal caregiver or having been a 'good' spouse (Bäckström & Sundin, 2010; Morgan & Laing, 1991; Murphy, 2005).

Constructed reciprocity referred to non-verbal cues recognised by the caregivers as reflecting the care recipient's implicit recognition of them and/or their effort (e.g., care recipient's smile). In some cases deterioration arising from an illness such as dementia resulted in the decline or disappearance of this type of reciprocity, although it is worth noting that that in some conditions, for example where communication was impaired, non-verbal reciprocity could acquire greater importance (Neufeld & Harrison, 1998).

Waived reciprocity related to situations where a care recipient could contribute little 'back' to the caregiver because of their condition, so caregivers 'waived' expectations of immediate reciprocity (Neufeld & Harrison, 1998). The desire to reciprocate (or to be reciprocated) had less significance.

Direct reciprocity referred – according to social exchange theories (Adams et al., 1976; Homans, 1961) – to a direct, immediate or short-term form of reciprocity, occasionally reported by caregivers as a motivating factor (Funk, 2012; Hsueh et al., 2008). For example, the care recipient helping look after the caregiver's children. Whilst most studies considered retrospective reciprocity as an important motivator, a contrasting view was also expressed by caregivers in two studies (one of which was exclusively focussed on the caregivers' perception of reciprocity) whereby reciprocity was considered insufficient to motivate the provision of informal care (Funk, 2012; Kim & Theis, 2000).

*Expected reciprocity* describes caregiving investment with an explicit view to maintaining or receiving future support. Various descriptors are used in the literature such as *the demonstration effect*, *generalised reciprocity*, or *preparatory reciprocity* and typically describe the provision of care for parents with an expectancy of their own children meeting any need for future support when they themselves need it (Albinsson & Strang, 2003; Donorfio & Kellett, 2006; Erickson, 2002; Funk,

2012; Globberman, 1996; Harris, 1998; Hsu & Shyu, 2003; Hsueh et al., 2008; Kim & Theis, 2000; Knight et al., 2016; Kodwo-Nyameazea & Nguyen P, 2008; Leichtenritt et al., 2004; Murphy, 2005; Neufeld & Harrison, 1998; Nkongho & Archbold, 1995; Sheu, 1997; Spitzer et al., 2003; Van Sjaak Geest, 2002; Wallroth, 2016; Wiles, 2002; Yamamoto & Wallhagen, 1997; Yeo et al., 2002).

Preparatory reciprocity also involves an investment – providing care for parents in order to model this to one's children but with more emphasis on instilling caring values than on getting care back in the future (Funk, 2012; Kodwo-Nyameazea & Nguyen P, 2008; Mahilall, 2006; Van Sjaak Geest, 2002; Wiles, 2002). The conditional character of this is seen in where the investment is perceived less as a hope and more as a kind of warranty, for example in an African context (Ghana) where a prerequisite of a parent accessing care from a child in the future was them having offered care to their own parents (Mahilall, 2006). Depending on the cultural model of caregiving the investment may not be constrained to one's own children as was the case within the Ghanaian culture where a desire to set a caregiving example to the wider community was described (Mahilall, 2006).

Some carers considered however that the demonstration effect was not a conscious or primary motivator for the support they provided (Dunér, 2010; Funk, 2012; Kim, 2009).

**2.2 Out of affection.** Love of the care recipient emerged as a key motivator, described variously as love, deeply felt love, natural love and sometimes as fidelity, emotional connectedness/togetherness or emotional attachment. Most caregivers referred to the affective properties of love (unconditional love, e.g., described as deeply felt love), while some perceived love more as a cognition (conditional love, e.g., love as a decision with specific expectancies attached). With respect to the latter, caregiving was seen as a demonstration of love within the relationship – internalised to the extent that love was discerned as an internal motivator increasing initial commitment and commitment to continue caring (Almeida et al., 2018; Bäckström & Sundin, 2010; Boeije et al., 2003; Browne Sehy, 1998; Cahill, 1999; Donorfio & Kellett, 2006; Erickson, 2002; Foster, 2012; Funk, 2012; Gerdner et al., 2007; Guberman et al., 1992; Harris & Long, 1999; Kim, 2009; Kuşçu et al., 2009; Lauritzen et al., 2019; Lewis et al., 1995; Lin et al., 2012; Mahilall, 2006; McDermott & Mendez-Luck, 2018; Mendez-Luck & Anthony, 2016; Merrill, 1996; Murphy, 2005; Nkongho & Archbold, 1995; Parveen et al., 2011; Pierce, 2001; Rivera et al., 2009; Russell, 2001; Sand et al., 2010; Statham, 2003; Sterritt & Pokorny, 1998; Strumpf et al., 2001; Sung, 1994; Vellone et al., 2002; Wallroth, 2016; Weinland, 2009; Zhang & Lee, 2019). The behavioural aspect of affection (love) was described as acting in a way that shows love to the care recipient (Jones et al., 2002; Mok et al., 2003). Devotion to care was seen as an expression of deep emotional affection (love) and as a behavioural aspect of affection, i.e., being devoted to the someone and to the caregiving tasks/role because of love (Arpanantikul, 2018; Dumit et al., 2015; Gerdner et al., 2007; Harris, 1998; Li et al., 2012; McDonnell & Ryan, 2014; Mok et al., 2003; Sand et al., 2010; Statham, 2003).

Where provision of care was perceived as a personal choice, motivation to provide care was described as emanating from a personal desire to care and was connected with empathy (e.g., recognition of a parent in need) and a close pre-morbid relationship with someone (see also the sub-theme of *relationship quality* presented below) (Lin et al., 2012; McDermott & Mendez-Luck, 2018; Murphy, 2005; Parveen et al., 2011; Statham, 2003; Sung, 1994; Williams et al., 2014). Feelings of compassion were less often expressed by caregivers as a motivator (Hinton et al., 2008; Jones et al., 2003).

**2.3 Relationship quality.** Motivations and willingness to provide care were described differently depending on whether the pre-existing relationship with the care recipient was characterised as positive, negative, reciprocal or non-reciprocal (Almeida et al., 2018; Anngela-Cole & Busch, 2011; Browne Sehy, 1998; Chao & Roth, 2000; Erickson, 2002; Hsueh et al., 2008; Kao & Stuijbergen, 1999; Kietzman et al., 2013; Lin et al., 2012; McDonnell & Ryan, 2014; Merrill, 1996; Morgan & Laing, 1991; Murphy, 2005; Neufeld & Harrison, 1998; Opie, 1994; Quinn, 2009; Statham, 2003; Wallroth, 2016; Williams et al., 2014; Yamamoto & Wallhagen, 1997). Good communication, sensitivity to each other's needs and emotional support in a relationship led to high positive caregiver motivation



when a care need arose. The pre-existing relationship quality (Anngela-Cole & Busch, 2011; Browne Sehy, 1998; Erickson, 2002; Kao & Stuijbergen, 1999; Kietzman et al., 2013; Lin et al., 2012; Merrill, 1996; Morgan & Laing, 1991; Murphy, 2005; Neufeld & Harrison, 1998; Quinn, 2009; Statham, 2003; Wallroth, 2016; Williams et al., 2014; Yamamoto & Wallhagen, 1997), especially the strength of the bond between the caregiver and care recipient, were key motivating factors (Almeida et al., 2018; Chao & Roth, 2000; Hsueh et al., 2008; McDonnell & Ryan, 2014; Opie, 1994). As well as reflecting pre-existing relationship quality, for some, caregiving was viewed as an opportunity to strengthen the relationship (which was itself a motivating factor) (Bäckström & Sundin, 2010; Foster, 2012; McDermott & Mendez-Luck, 2018; Mendez-Luck & Anthony, 2016; Öhman & Söderberg, 2004; Sand et al., 2010; Stajduhar et al., 2008; Statham, 2003; Tretteteig et al., 2017b).

A care recipient's expectations or attitudes towards the caregiver and towards the care they received emerged as crucial influences on caregiver motivations and willingness to continue caring. Whether the care recipient demonstrated a positive/negative attitude towards the caregiver (in the form of expressed favour or dislike) or expressed their gratitude or not for the care received, influenced caregivers' motivations and willingness to care. The influence of gratitude was clear – caregivers felt more motivated if the support they provided was reciprocated or acknowledged, including both verbal and non-verbal acknowledgement (Almeida et al., 2018; Boeije et al., 2003; Holroyd, 2003; Murphy, 2005; Sand et al., 2010; Stajduhar et al., 2008; Statham, 2003; Williams et al., 2014; Yamamoto & Wallhagen, 1997).

Another important influence on caregiver motivation was the care recipient's level of dependence on the caregiver, particularly where the relationship became more asymmetric and demanding (Guberman et al., 1992; Quinn, 2009; Statham, 2003; Tretteteig et al., 2017b). The care recipient's level of communicative ability was identified in studies specific to dementia caregivers, with a care recipient's deterioration in communicative ability in some cases decreasing motivations to provide care (Foster, 2012; Guberman et al., 1992; Lin et al., 2012; Murphy, 2005; Pang & Lee, 2019; Quinn, 2009; Statham, 2003; Sterritt & Pokorny, 1998; Tretteteig et al., 2017b; Vellone et al., 2002).

**2.4 Family values.** Family values are at the core of familism: a strong identification with an idea of 'family' (Donorfio & Kellett, 2006; Dunér, 2010; Guberman et al., 1992; Harris, 1998; Hinton et al., 2008; Ho et al., 2003; Kim, 2009; Nkongho & Archbold, 1995; Parveen et al., 2011; Pierce, 2001; Spitzer et al., 2003; Sterritt & Pokorny, 1998; Tretteteig et al., 2017b; Wallroth, 2016), underlying motivations to provide care. Strong familial values were expressed in terms of familism and blood relations, which in some cases were enhanced culturally (e.g., by norms maintaining high familism) (Cahill, 1999; Muoghalu & Jegede, 2010). Another example of the influence of family values was seen in how other caregivers express the importance of family as '*family ties*' (Arpanantikul, 2018; Gerdner et al., 2007; Jones et al., 2002). In the context of family, it was also noticeable that some caregivers functioned in the role of a kin-keeper, maintaining family cohesion and continuity through taking on the caregiving role, which related to taking responsibility for family communications and connectedness (Albinsson & Strang, 2003; Harris, 1998; Jones et al., 2002; Kim, 2009; Kuşçu et al., 2009; Ng et al., 2016; Nkongho & Archbold, 1995; Sheu, 1997; Sung, 1994; Zhang & Lee, 2019).

Related to one aspect of family values, i.e., the idea how caregivers felt they should treat their family members, was the protection of the dignity and self-esteem of people with care and support needs. For some caregivers, caring was motivated by a desire to protect the dignity and self-esteem of the care recipient that caregivers 'assumed' would be lost on entering or receiving various types of formal care. Treating individuals with respect was an important factor – particularly respect for a parent including exceptional deference and/or courtesy, displaying earnest consideration of them (Clark & Huttlinger, 1998; Nkongho & Archbold, 1995; Sand et al., 2010; Strumpf et al., 2001; Sung, 1994; Van Sjaak Geest, 2002; Vellone et al., 2002).

**2.5 Obligations to provide care.** A sense of obligation to care was prevalent with the two main categories identified: (1) *actual obligation to provide care* and (2) *perceived obligation*. We can distinguish

further between negative and positive caregiving obligations, with actual obligations discerned as negative and perceived obligations being either negative or positive. Based on the evidence reviewed, we propose that the presence or absence of actual choice (underpinned by the availability of care options) distinguishes between the actual and perceived obligations to provide care, whereas the perception of choice (demonstrated later) distinguishes between positive and negative perceived obligations. The following patterns were identified as part of (1) *actual obligation to provide care*: (a) obligation based on the (actual) lack of alternatives and (b) obligation with guilt. *Perceived obligation* (2) also included variants: (c) moral obligation, (d) filial obligation, (e) spousal obligation, (f) extended familial obligation, (g) collective obligation.

*Actual obligation* (1) was referred to as negative obligation, i.e., with caregiving viewed as a duty imposed by social rules and traditions, often described as something caregivers 'have to do' or that they 'can't walk away from'. This type of obligation was accompanied either with (a) the (actual) lack of alternatives and/or (b) feelings of guilt (Albinsson & Strang, 2003; Bäckström & Sundin, 2010; Cahill, 1999; Donorfio & Kellett, 2006; Erickson, 2002; Foster, 2012; Funk, 2012; Murphy, 2005; Statham, 2003; Tretteteig et al., 2017a; Williams et al., 2014; Zhang & Lee, 2019), strongly suggesting an extrinsic character to these motives. Obligation arising from the (a) *the lack of alternatives* to undertake the caregiving responsibilities was amongst the most obvious external motivators in informal caregiving, persistently recalled by caregivers (Almeida et al., 2018; Alonso et al., 2018; Aronson, 1992; Cahill, 1999; Cash et al., 2013; Erickson, 2002; Holroyd, 2001; Kietzman et al., 2013; Lee et al., 2019; Leichtentritt et al., 2004; Lin et al., 2012; Merrill, 1996; Murphy, 2005; Ng et al., 2016; Parveen et al., 2011; Statham, 2003; Wallroth, 2016; Wiles, 2002; Zhang & Lee, 2019). This type of obligation was sometimes accompanied by (b) *obligation with guilt*, i.e., feelings of failing in one's duty or letting someone down if care is not provided (Albinsson & Strang, 2003; Bäckström & Sundin, 2010; Cahill, 1999; Donorfio & Kellett, 2006; Erickson, 2002; Foster, 2012; Funk, 2012; Murphy, 2005; Statham, 2003; Tretteteig et al., 2017a; Williams et al., 2014; Zhang & Lee, 2019).

*Perceived obligation* (2) and the subsequent identified variants of this type of obligation (c–g) could be either positive or negative dependent on the perception of choice, whereby this perception of choice was understood as an extent to which the caregiver believed they had autonomy to accept/agree with the potential caregiving responsibility currently or in the future rather than the actual choice determined by the availability of caregiving alternatives. Thus, perceived obligation was negative with the perception of no choice and positive when the choice was perceived as present. It was clearly noticeable that positive obligation related to more intrinsic motives (including affectionate emotional involvement).

Moral beliefs about caregiving as a duty shaped the sense of (c) *moral obligation* (conscience and moral reasoning, moral principles), often expressed by caregivers saying that 'you do the right thing' or that 'your conscience is clear' (Cahill, 1999; Clark & Huttlinger, 1998; Donovan & Williams, 2015; Dunér, 2010; Kao & Stuifbergen, 1999; Sterritt & Pokorny, 1998; Wallhagen & Yamamoto-Mitani, 2006; Wallroth, 2016; Williams et al., 2014; Zhang & Lee, 2019).

*Filial obligation* (d) signalled a strong motivation for caregiving amongst adult–child caregivers in Asian studies influenced by a cultural ideology of *filial piety*. The symbols of filial piety included: respect, repayment and taking care of parents at home (Chao & Roth, 2000; Han et al., 2008; Hinton et al., 2008; Ho et al., 2003; Holroyd, 2001; Hsu & Shyu, 2003; Hsueh et al., 2008; Jones et al., 2002; Jones et al., 2003; Kao & Stuifbergen, 1999; Kim & Theis, 2000; Kong et al., 2010; Lee et al., 2019; Li et al., 2012; Meyer et al., 2015; Ng et al., 2016; Park, 2012; Qiu et al., 2018; Sheu, 1997; Spitzer et al., 2003; Zhang & Lee, 2019). This sense of *filial obligation* and responsibility was paramount in studies conducted also outside the Asian context and was not constrained to the underlying cultural value of filial piety (Alonso et al., 2018; Anngela-Cole & Busch, 2011; Bashir, 2014; Bryant & Lim, 2013; Donorfio & Kellett, 2006; Donovan & Williams, 2015; Dumit et al., 2015; Erickson, 2002; Harris, 1998; Jones et al., 2002; Kodwo-Nyameazea & Nguyen P, 2008; Kristanti et al., 2019; Kuşçu et al., 2009; McDermott & Mendez-Luck, 2018; Ng et al., 2016; Sasat, 1998; Sheu, 1997; Strumpf et al., 2001; Sung, 1994; Vellone et al., 2002; Wallroth, 2016).

*Spousal obligation* (e) to provide care was largely attributed to strong influences of cultural/societal values and beliefs described as 'loyalty' or 'obligation' or 'commitment' arising from marriages or partnerships. Marriages per se were reported as the reason for informal caregiving (Albinsson & Strang, 2003; Almeida et al., 2018; Bäckström & Sundin, 2010; Boeije et al., 2003; Cahill, 1999; de Leon Arabit, 2005; Globerman, 1996; Harris & Long, 1999; Ho et al., 2003; Holroyd, 2003; Holroyd, 2005; Hsu & Shyu, 2003; Kim, 2009; Kim & Theis, 2000; Lauritzen et al., 2019; Lin et al., 2012; Murphy, 2005; Parveen et al., 2011; Qiu et al., 2018; Rivera et al., 2009; Sasat, 1998; Statham, 2003; Vellone et al., 2002; Weinland, 2009; Zhang & Lee, 2019). In some cases, the desire to support a marital relationship by taking care of a spouse's relative motivated the provision of care. For example, female caregivers caring for a parent-in-law (Globerman, 1996).

*Extended familial obligation* (f) refers to the situation in which different family members felt responsible for supporting the family unit, often influenced by affective ties or a close kin relationship. In some studies an entire family was expected (culturally) to be involved in caring for a family member (Anngela-Cole & Busch, 2011; Knight et al., 2016; Kodwo-Nyameazea & Nguyen P, 2008; Muoghalu & Jegede, 2010; Murphy, 2005; Yeo et al., 2002).

The notion of (g) *collective obligation* means that the individual is embedded in community relationships and is expected to fulfil their obligations to the collective community (rather than familial relationships only). Distinctive examples from the African cultural contexts are provided in online S2 Supplementary File whereby the traditional care arrangements are such that the community and the family care for the person with care needs (Gurayah, 2015; Mahilall, 2006; Muoghalu & Jegede, 2010).

### **Theme 3: personal characteristics, beliefs and resources**

This theme incorporates five descriptive subthemes: caregiver's personal characteristics and inner resources; caregiving experience and expertise; coping; finding meaning; illness perceptions.

**3.1 Caregiver's personal characteristics and resources.** The subtheme refers to personal characteristics (such as caregiver's physical ability or health status) (Bryant & Lim, 2013; Funk, 2012; Williams et al., 2014) and inner resources (e.g., being knowledgeable, tolerant or organised), including caregivers' natural affinity for caregiving (which could be discerned as a personality trait – being a caring person, having a 'caring nature') (Almeida et al., 2018; Jones et al., 2003; McDermott & Mendez-Luck, 2018; Opie, 1994; Parveen et al., 2011; Yamamoto & Wallhagen, 1997). Dispositional optimism was evident and included: hoping for a miracle; maintaining hope and focussing on positive aspects of life to facilitate continued caregiving (Guberman et al., 1992; Mok et al., 2003; Sand et al., 2010; Vellone et al., 2002; Zhang & Lee, 2019). Optimistic beliefs were strongly linked to positive motivations to continue providing care.

**3.2 Caregiving experience and expertise/competence.** Previous caregiving experiences and having a sense of competence in the role or aspects of it, shaped willingness to provide care and engendered feelings of security, resilience or confidence in the current caregiving role (Kim, 2009; Kuşçu et al., 2009; Øydgard, 2017; Stajduhar et al., 2008). Furthermore, previous experience in dealing with illness and death was sometimes reported as a motivator to provide the current care (Mahilall, 2006).

**3.3 Caregiver coping responses.** Coping refers to the different ways (cognitive, emotional, behavioural) caregivers respond to their caregiving situation and the challenges it can present. In the reviewed evidence, coping strategies played an important role in maintaining (or not) the role rather than initial decisions to provide care, i.e., the way caregivers coped with their *current* situation influenced mainly their motivations and willingness to continue to provide care. Caregiving motivations and willingness also fed back bidirectionally to caregivers' coping responses. The range of coping strategies indicated by caregivers reflected the dynamic and contextual nature of appraisals,

the caregiving context, and the perceived and/or actual availability and effectiveness of formal and informal support (Williams et al., 2014).

Several taxonomies defining coping and the dimensions therein exist (e.g., Carver et al., 1989; Lazarus & Folkman, 1984), yet here we present caregiver situational coping responses which emerged from the inductive synthesis of the data by grouping them into two categories: 'Facing a stressor' and 'Avoiding a stressor'. Under each of these categories, specific coping strategies and their relation to motivations are described.

'Facing a stressor' refers to individual coping strategies which actively or directly deal with a perceived stressor, for instance by planning activities that the care recipient can engage in. It was discerned in three dimensions. The first one referred to strategies which involved a *positive reframing and acceptance of the current situation*. For example, upward social comparison, i.e., comparing with other worse health conditions than their care recipient had, was mentioned in one study as maintaining motivation to provide care (Foster, 2012). Accepting the role helped the caregiver to adjust to their role (Boeije et al., 2003). Daily routines, where possible to put in place, were experienced as reassuring, providing structure to life, and offering a sense of control. Some caregivers considered that their role became less burdensome over time due to the care duties becoming habitual – acceptance enabling the establishment of 'a new normal' and a shift in priorities and goals (Albinsson & Strang, 2003; Boeije et al., 2003; Clark & Huttlinger, 1998; Donorfio & Kellett, 2006; Foster, 2012; Gurayah, 2015; Parveen et al., 2011; Sand et al., 2010; Tretteteig et al., 2017a; Tretteteig et al., 2017b; Zhang & Lee, 2019). The second dimension of 'facing a stressor' referred to mainly *seeking and using (informal and formal) support*, including *engagement in religious practices* as means of emotional and social support. Social-emotional coping was seen in seeking informal social (emotional or practical) support, with the perceived or actual availability of family support playing an important role in shaping both initial and continued motivation and willingness to provide care. Having access to appropriate practical support (as needed) within the family helped some continue with caregiving and, where available, caregivers drew upon direct help from family members in providing care and/or help via support with other tasks including caring tasks, tasks not associated with the caring and financial assistance. Family support was often fundamental to shaping motivations. It helped shape positive views about caregiving which then influenced whether caregivers felt able and willing to continue in their role (continuation motivation). A decision to become the main caregiver in the first place had been based on the availability of other family support (initial motivation) (Bryant & Lim, 2013; Erickson, 2002; Gerdner et al., 2007; Guberman et al., 1992; Han et al., 2008; Harris, 1998; Holroyd, 2003; Jones et al., 2002; Lee et al., 2019; Lewis et al., 1995; Lin et al., 2012; McDonnell & Ryan, 2014; Merrill, 1996; Meyer et al., 2015; Parveen et al., 2011; Qiu et al., 2018; Rivera et al., 2009; Sterritt & Pokorny, 1998; Wallroth, 2016; Weinland, 2009; Williams et al., 2014; Zhang & Lee, 2019). Although coping by means of family care sharing (e.g., between siblings) and/or through rotating duties was found helpful and motivating (Gerdner et al., 2007; Kim, 2009; Merrill, 1996; Meyer et al., 2015; Murphy, 2005; Tretteteig et al., 2017b), these studies did not relate care sharing to relationship quality and a shared understanding of one another's roles and responsibilities. Family support also acted as a means of socialising which for some caregivers provided links to their '*normal life*' (Alonso et al., 2018; de Leon Arabit, 2005; Kristanti et al., 2019; Lin et al., 2012; Meyer et al., 2015; Sterritt & Pokorny, 1998; Tretteteig et al., 2017b) which was understood as a life alongside caregiving. Finally, approach-oriented emotional-social coping strategies also related to the use of formal social support, with organised caregiver groups being reported as a mainly positive source of support (Lauritzen et al., 2019; Lin et al., 2012; Meyer et al., 2015). Formal support groups elicited feelings of connectedness with other caregivers which could help caregivers to reframe their situation and expectancies, reducing the perception that they are the only ones in such a situation (Zhang & Lee, 2019), at the same time upholding the continued motivation and willingness to provide care.

Religiosity was expressed as central in some caregivers' lives with spirituality and prayer the most used coping strategies. Drawing on one's faith, religious or spiritual support was considered as a

source of emotional social support, thought to have helped in coping with some of the stresses associated with caregiving (Browne Sehy, 1998; Chao & Roth, 2000; de Leon Arabit, 2005; Donovan & Williams, 2015; Gerdner et al., 2007; Hinton et al., 2008; Jones et al., 2002; Lin et al., 2012; Mars, 2015; Meyer et al., 2015; Muoghalu & Jegede, 2010; Nkongho & Archbold, 1995; Pang & Lee, 2019; Qiu et al., 2018; Sterritt & Pokorny, 1998; Tretteteig et al., 2017a; Weinland, 2009).

The third dimension of 'facing a potential stressor' referred to *planning and actively addressing practical caregiving needs*. Preparing for caregiving through thinking about it, using formal support (e.g., home care services, respite care services) where possible and planning for the future (e.g., care plans where professionals were involved in care planning) were helpful in sustaining continued motivations for caring (Foster, 2012). Where caregivers had an opportunity to use respite care services, the temporary alleviation of the caregiver burden caused an increase in subsequent motivation (Russell, 2001; Sterritt & Pokorny, 1998; Tretteteig et al., 2017a; Tretteteig et al., 2017b). The ability to have breaks from caregiving worked as a catalyst for subsequent coping with caring duties. Interestingly, the evidence did not report the negative consequences that availing of respite care services may lead to, for example, caregiver sense of guilt or anxiety, as reported in a scoping review (Seddon & Prendergast, 2019). Engaging in leisure activities was a way to maintain a sense of balance which enhanced motivations for continuing with caring, but this was not available to all caregivers (de Leon Arabit, 2005; Foster, 2012). Home support services (e.g., cleaning or household assistance, community nursing care) were viewed as a lifeline for some caregivers, with the additional time for themselves it offered contributing to higher motivation and willingness to continue caring (Gerdner et al., 2007; Lewis et al., 1995; McDonnell & Ryan, 2014; Öhman & Söderberg, 2004). Challenges associated with the organisation, reliability and flexibility of care and support services are known to sometimes increase caregiver sense of frustration (Heath et al., 2018), however, they were not mentioned in the reviewed literature.

'Avoiding a stressor' embraced coping strategies focused on distraction, diversion, or social isolation. It was discerned in three dimensions. The first one referred to the *use of humour (as a defensive measure)* and *cognitive diversion*, it helped maintain motivations to care by making light of aspects of the current situation (Bäckström & Sundin, 2010; Stajduhar et al., 2008; Statham, 2003; Tretteteig et al., 2017a). Caregivers using these strategies seemed to be more willing to provide care compared to caregivers using the remaining two avoidant-oriented coping dimensions. The second dimension pertained to the caregiver *choosing social isolation* (e.g., because of being embarrassed by the care recipient's illness). This impacted negatively on their motivation to continue caring as isolation was experienced both as desired and painful (Albinsson & Strang, 2003; McDonnell & Ryan, 2014; Mok et al., 2003; Ng et al., 2016; Stajduhar et al., 2008; Zhang & Lee, 2019). The third coping response referred to an example of *action distraction* – through engaging oneself in caregiving tasks (immersion in the caring role), i.e., actively coping by taking action to deal with caregiving tasks (e.g., focusing instrumentally on the caring tasks) to ameliorate the situation and reduce the existing demands which may be challenging. It enabled dealing with caregiving effectively but with important constraints: engaging oneself in instrumental and emotional caregiving work may have been efficient in the short-term but in the long run it could lead to burn out and had adverse effects on continuous motivation and willingness to care (McDonnell & Ryan, 2014).

**3.4 Finding meaning.** Finding meaning as a subtheme related to the cognitive, emotional, and existential components of caregiving. The cognitive aspect was a way of making sense of caregiver experiences; the emotional aspect was understood as caregiver satisfaction and fulfilment; and the existential aspect pertained to making a choice in caregiving and the issue of responsibility. Finding meaning and meaning making have a motivational component, either understood as the motivation for caring or as a way that motivates the caregiver to continue caring.

It is worth noting that the concepts of 'finding meaning' or 'meaning making' have been interpreted differently (Quinn, 2009). Some researchers consider 'meaning' in two dimensions, i.e., a cognitive one which pertains to beliefs held about caregiving experience, and an emotional one which

relates to satisfaction with the caregiving role (Noonan & Tennstedt, 1997). Similarly, it is also discerned as two separate processes – searching for meaning and finding meaning (Farran & Keane-Hagerty, 1991; Noonan & Tennstedt, 1997). With respect to finding meaning, this was often interpreted as reflecting the positive aspects of caregiving (Kasten, 1993; Quinn & Toms, 2019), e.g., gaining satisfaction through acting on personal values or beliefs. There are those who consider finding meaning as part of the coping process (Pearlin et al., 1990), ‘meaning’ is a mediator of the stress process (Pearlin et al., 1990). Pearlin and colleagues (Pearlin et al., 1990) conceptualised ‘finding meaning’ as a mechanism involving the reduction of expectations, the use of positive comparisons and a search for a larger sense of the illness. For others, finding meaning is part of existential discourse (Farran & Keane-Hagerty, 1991; Frankl, 2011) with meaning found through making choices or emergent from searching for a day-to-day sense of purpose or an ultimate (spiritual/philosophical) meaning (Levine et al., 1984).

Within this review finding meaning – a relatively large subtheme – is a broad concept with *many dimensions* relevant to the caregiving experience in terms of motivations for providing care. Therefore, we do not constrain the concept to ‘coping strategy’ (subtheme 3.4) but present it in its wider perspective. Caregiving can give a sense of purpose, an appreciation for life and enable personal growth (understood as both expanding and transcending the self and experiencing authenticity in existence). These are strong intrinsic motivators for caregiving.

Caregivers made meaning of their past caring experiences and the reflection accompanying this was seen to be a powerful motivator to continue to care (Alonso et al., 2018; Harris, 1998; Jones et al., 2003; Öhman & Söderberg, 2004; Pang & Lee, 2019; Pelusi, 1999; Russell, 2001; Sand et al., 2010; Wallroth, 2016; Zhang & Lee, 2019). Some caregivers expressed how caring had brought a new perspective on living, which was felt to be fuller and authentic (*you appreciate life more*). This was often realised due to a growing awareness of the shortness of life consequent to the care recipient’s health condition (Albinsson & Strang, 2003; Öhman & Söderberg, 2004). The importance of having good memories, finding meaning in what is past, was also evident as a motivator of caregiving (Albinsson & Strang, 2003; Pierce, 2001).

The emotional component of finding meaning referred to the feelings of personal satisfaction or happiness derived from having helped the care recipient, described by some as *‘being happy from within’* (Kuşçu et al., 2009; Mahilall, 2006; Murphy, 2005; Ng et al., 2016). Caregiving was also perceived as an opportunity for self-growth, prompting continued motivation (Jones et al., 2003; Sand et al., 2010; Yamamoto & Wallhagen, 1997), and gaining a sense of purpose for living was also seen in the data (see S2 Supplementary File for quotes). The act of caregiving gave direct meaning to the caregiver’s life with terms such as *‘vocation’, ‘calling’, ‘purpose’, ‘mission’, ‘engulfed’* being used to describe their experience. Notably, such feelings extended beyond motivations to care as it was considered as providing a main and general purpose for living (Dunér, 2010; Guberman et al., 1992; Holroyd, 2005; Jones et al., 2002; Mars, 2015; Mok et al., 2003; Öhman & Söderberg, 2004; Statham, 2003; Williams et al., 2014).

For some, caregiving served a purpose of finding new meaning in a previously difficult or complicated relationship (Tretteteig et al., 2017a; Wallroth, 2016; Zhang & Lee, 2019) with caregiving motivated by a desire to reconnect or make up for lost time with a care recipient, building a connection that, mainly adult child caregivers, never had as children.

**3.5 Seeing care recipient’s illness.** The subtheme describes caregivers’ thoughts about their care recipient’s illness (including the attributions of cause of the care recipient’s illness, the perceived severity of illness) as linked to their motivations/willingness for caring.

Caregivers spoke differently about their willingness to care depending on where they attributed the cause for their care recipient’s illness. For example, if an illness was perceived to be a care recipient’s fault (e.g., God’s punishment for their misdeeds), then caregivers seemed less willing to provide care in the first place. On the contrary, if the illness was discerned as a natural life process (*‘a law of nature’*), caregivers were more accepting of the role (Hinton et al., 2008; Muoghalu

& Jegede, 2010; Pang & Lee, 2019; Wallhagen & Yamamoto-Mitani, 2006; Williams et al., 2014; Yeo et al., 2002).

The perceived severity of a care recipient's illness was also important. For example, caregivers found it difficult to watch an illness 'breaking down' the care recipient (as reported in studies of those with dementia) and gave this as the reason for deciding to place the care recipient in a nursing home (Öhman & Söderberg, 2004; Quinn, 2009), i.e., motivation to discontinue caring.

## Discussion

### Summary of findings

This paper synthesised findings from 103 studies from a wide range of cultures and countries spanning three decades, with data from over two thousand and five hundred caregivers across a range of health conditions. Diverse determinants underlying motivations and willingness to provide care were identified, with this paper addressing those of a contextual, personal and interpersonal nature.

Key factors impacting caregivers' motivation and willingness to provide care included: (1) wider contextual and temporal aspects of caregiving which can modify beliefs, expectations, experiences and thus motivations; (2) interpersonal relationships, familial relationships or relationships within the wider community, specifically highlighting reciprocity, obligation and family values; (3) individual characteristics, illness perceptions, coping resources and responses that enabled caregivers to undertake and/or carry on with their role.

We have high confidence in the two analytic themes of relational and contextual themes and moderate confidence in the theme focusing on personal characteristics. Whilst multi-level factors influenced motivations and willingness to provide care it must be noted that the reviewed studies did not typically distinguish between the concepts of motivations and willingness to provide informal care, and these were not distinguishable in the caregivers' accounts. This highlights the conceptual confusion around the constructs of motivations and willingness to provide care. We propose that motivations to provide care may be a more primary construct in comparison to willingness to continue caring with regards to specific tasks (e.g., practical, emotional, or personal care) – although willingness may affect motivations (i.e., a bidirectional relationship between the two concepts).

Our findings from studies of caregiving across a range of health conditions are consistent with Greenwood & Smith's systematic review of 26 qualitative studies of dementia informal caregiver motivations (Greenwood & Smith, 2019) whereby multiple reasons underlying informal care provision are identified. The significance of the fluctuating nature of motivations is highlighted in their findings, however, we evidence greater effect of relationship type and quality, and country of origin. Unlike their review the evidence presented here strongly suggests differences not only 'between' caregivers (e.g., relationship type) but also 'within' caregivers (e.g., over time), highlighting the complex and dynamic nature of caregiving. One example of variation at a macro level is that *relationship quality* as a motivating factor was less evident in Asian caregiver studies ( $N = 5$ ) (Chao & Roth, 2000; Hsueh et al., 2008; Kao & Stuijbergen, 1999; Li et al., 2012; Yamamoto & Wallhagen, 1997) than amongst Caucasian caregivers studies ( $N = 11$ ) (Bäckström & Sundin, 2010; Foster, 2012; McDonnell & Ryan, 2014; Merrill, 1996; Öhman & Söderberg, 2004; Quinn, 2009; Sand et al., 2010; Stajduhar et al., 2008; Tretteteig et al., 2017b; Wallroth, 2016; Williams et al., 2014). Similarly, whilst it may seem that motivations of both adult children and spousal caregivers are very similar, the mechanisms of caregiving motivations revealed in this qualitative synthesis highlight differences. To provide a specific example – Greenwood & Smith (Greenwood & Smith, 2019) highlight the commonalities across cultures and terminology in terms of obligation to provide care with terms such as filial piety, duty, obligation and responsibility being discussed as synonymous and being rather negative. Many terms around 'obligation' are used interchangeably. We have shown however that they differ, both in relation to motivations and willingness to provide care, but also in the extent

to which they can be considered negative. There is, for example, a difference in the experience of filial obligation versus spousal obligation (see subtheme 2.7). Through the synthesis we distinguished also between different types of reciprocity (e.g., retrospective and expected reciprocity and in-kind variations – see subtheme 2.1 and 2.2). Our meta-synthesis findings demonstrate the diversity, multi-facetedness and often uniqueness of motivations, emphasising and evidencing that there is no universal, ‘one size fits all’ finding in relation to caregiving motivations and willingness to provide care.

### **Reflections on implications of findings in relation to key frameworks, theories and research**

There are numerous theoretical frameworks within which caregiver motivations can be considered (Zarzycki & Morrison, 2021), however we focus on that which was most robustly considered within caregiver research, i.e., *Commitment Theory* (Al-Janabi et al., 2018; Aranda & Knight, 1997) and *Self-determination Theory (SDT)* (Ryan & Deci, 2000). This review identifies internal (e.g., caregiver affection) and external (e.g., geographical proximity to the care recipient) factors that influence caregiver commitment as considered in *Commitment Theory* (Al-Janabi et al., 2018; Aranda & Knight, 1997). SDT theory gave rise to the distinction of intrinsic and extrinsic motivations. The caregiver motivations presented in this review however appear not to conform to this basic dichotomy. Instead, our findings identify a diversity of motives both between and within caregivers and suggest that (a) it is often difficult to establish whether the motivation is intrinsic or extrinsic (or autonomous, introjected, external) and (b) motivations to care can be multiple, and can include intrinsic and extrinsic motivations that need not be mutually exclusive (e.g., caregiving out of both love and obligation). This coexistence may explain the inconsistent results reported in the literature (e.g., Asahara et al., 2002; BurrIDGE et al., 2007; Chao & Roth, 2000; Farran & Keane-Hagerty, 1991; Frankl, 2011; Kasten, 1993; Lyonette & Yardley, 2003; Muoghalu & Jegede, 2010; Nkongho & Archbold, 1995; Pearlin et al., 1990; Quinn & Toms, 2019; Romero-Moreno et al., 2017; Sasat, 1998) and begs the question of whether the popular, simple dichotomy around extrinsic and intrinsic caregiving motivations (Feeney & Collins, 2003; Kim et al., 2015; Lyonette & Yardley, 2003; Quinn et al., 2010; Quinn et al., 2012; Walker et al., 1990) is sufficient to develop our understanding of caregiver behaviours. If it is not, as our findings suggest, how should these concepts be defined and operationalised in future research? We indicate that the theories should consider multifaceted nature of motivations which cannot be easily classified into discrete categories. Based on the evidence of this systematic review we advise against generalised and simplified theoretical approaches to studying caregiving motivations, if the research based on these theories is to comprehensively reflect caregiver experience.

Several taxonomies defining coping and the dimensions therein exist (e.g., Carver et al., 1989; Lazarus & Folkman, 1984). The findings of this review present two groupings of coping strategies which emerged from the inductive synthesis, i.e., ‘facing a stressor’ and ‘avoiding a stressor’. These can be referred to approach – versus avoidance-oriented coping (Finset et al., 2002; Parker & Endler, 1992), with each dimension of the groupings represented by cognitive-emotional, socio-emotional and action-oriented strategies, as described below. Each of these coping domains is evidenced to influence caregiving motivations and willingness to care. *Approach-oriented coping* refers to individual strategies which actively or directly deal with a perceived stressor, for instance by planning activities that the care recipient can engage in. *Avoidance-oriented coping* relates to either a passive or disengaged way of dealing with stressors or engaging actively in things other than the stressor, including denial, diversion, or escape.

The approach-oriented *cognitive-emotional coping domain* includes responses such as follows: being grateful for the current situation (positive reframing); taking control and accepting the situation; the *emotional-social domain* contains: attending one’s own needs; using available family support; seeking formal social support; engaging in religious practices; and the *action-related*



*domain* encompasses: preparing for caregiving (planning); using respite care and short break support; having ‘me’ time; using formal home care services.

The avoidance-oriented *cognitive-emotional coping domain* includes using humour (as a defensive strategy) and viewing care recipient’s anticipated death as a rescuer; the *emotional-social domain* describes seeking social isolation; and the *action-related domain* refers to distracting oneself through focusing on caregiving personal care tasks.

Caregiving has traditionally been considered as a potentially stressful experience, with caregivers drawing on different resources as a means of coping with the demands the role may place on them. The influential Stress Process Model (Pearlin, 1994; Pearlin et al., 1990) proposed that caregivers go through a developmental process in adapting to the stress-generating events they encounter – and our review supports this (Boeije et al., 2003; Browne Sehy, 1998; Foster, 2012; Hsu & Shyu, 2003; Lin et al., 2012; Opie, 1994; Parveen et al., 2011; Williams et al., 2014). The model has, however, been criticised for focusing on negative caregiving outcomes with more recent research highlighting positive aspects of caregiving, such as uplifts and gratification (Kramer, 1997; Quinn & Toms, 2019; Yu et al., 2018). Our findings support this (e.g., de Leon Arabit, 2005; Dunér, 2010; Holroyd, 2005). As caregiving is a complex process, one could expect many factors would influence how the caregiver adapts to the stresses of caregiving. The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984; Lazarus & Smith, 1988) and a socio-cultural model of stress, which integrates culture within the previous theoretical framework (Aranda & Knight, 1997), have also been popular in this domain. An important aspect of these models is that caregiver outcomes may be less a result of the caregiving tasks or the intensity of care, but more a result of the appraisals of these tasks and the caregiving situation. In our findings caregiver appraisals, coping and use of social support were certainly salient factors impacting caregivers’ motivations and willingness to provide care (Erickson, 2002; Wallroth, 2016; Holroyd, 2003; Muoghalu & Jegede, 2010; Gurayah, 2015; Parveen et al., 2011; Lauritzen et al., 2019; Bäckström & Sundin, 2010; McDonnell & Ryan, 2014; Rivera et al., 2009; Boeije et al., 2003; Statham, 2003; Chao & Roth, 2000; Albinsson & Strang, 2003; Lin et al., 2012; Sand et al., 2010; Foster, 2012; Öhman & Söderberg, 2004; Tretteteig et al., 2017a; Williams et al., 2014; Tretteteig et al., 2017b; Bryant & Lim, 2013; Browne Sehy, 1998; Lee et al., 2019; Donovan & Williams, 2015; Han et al., 2008; Hinton et al., 2008; Jones et al., 2002; Meyer et al., 2015; Guberman et al., 1992; Murphy, 2005; Nkongho & Archbold, 1995; Sterritt & Pokorny, 1998; Donorfio & Kellett, 2006; Mok et al., 2003; Harris, 1998; Kim, 2009; Clark & Huttlinger, 1998; Merrill, 1996; Weinland, 2009; Lewis et al., 1995; de Leon Arabit, 2005; Russell, 2001; Mars, 2015; Neufeld & Harrison, 1998; Ng et al., 2016; Stajduhar et al., 2008; Gerdner et al., 2007; Alonso et al., 2018; Qiu et al., 2018; Zhang & Lee, 2019; Kristanti et al., 2019; Pang & Lee, 2019). Review findings point to the bidirectionality of the relationship between motivations and willingness to continue providing care and current caregiver coping responses, highlighting a vital part played by the latter in maintaining the continued motivations (see subtheme 3.4). Longitudinal studies exploring the associations between coping responses and motivations comprise an important research gap; longitudinal evidence could contribute to understanding of the caregiver coping processes.

Although our synthesis has usefully identified determinants of motivations and willingness to provide care, further prospective study of relationships between motivations to provide care and subsequent caregiver outcomes is required. In addition, future studies should address the ongoing confusion around the definitions of motivations and willingness to provide care and the methods of assessing these concepts.

### **Implications for policy and practice**

As stated, assumptions exist in many current societies that family members provide care for a relative if it becomes necessary. This implies, and indeed is borne out by evidence, that not everyone exercises choice to become a caregiver (Almeida et al., 2018; Alonso et al., 2018; Aronson, 1992; Cahill, 1999; Cash et al., 2013; Erickson, 2002; Holroyd, 2001; Kietzman et al., 2013; Lee et al., 2019;

Leichtentritt et al., 2004; Lin et al., 2012; Merrill, 1996; Murphy, 2005; Ng et al., 2016; Parveen et al., 2011; Statham, 2003; Wallroth, 2016; Wiles, 2002; Zhang & Lee, 2019). The choice to provide care is defined as the extent to which a caregiver believes they had the freedom to assume the caregiving role (Al-Janabi et al., 2018). When caregiving is described, in caregiver's own words, as something they 'have to do' and they 'can't walk away from' (as seen in subtheme 2.7), this suggests little free choice was had. This review supports the imperative cautioning against making assumptions about willingness to provide care.

Given the importance of actual and perceived choice in shaping motivations and willingness to provide care, and the range of factors that may influence actual/perceived choice, we suggest that (a) the complex and diverse motives that drive caregivers in their roles (which are not generally acknowledged) should be given more attention by policy-makers and practitioners, (b) motivations and drivers must not be taken for granted over time as they are not static, and (c) where applicable this should be supported by relevant policies and be reflected in discussions that take place during a caregiver assessment (as employed in the British context) (Seddon & Robinson, 2015). A carer assessment is especially important with regards to changing personal and contextual (situational) factors that may modify caregiver motivations, willingness, and ability to provide care.

The wider situational and temporal contexts within which caregiving is situated affect the extent to which relational and personal aspects gain dominance. For example, 'convenience factors' such as being the only child are amongst those often making the caring role necessary. Therefore, we indicate that policy should highlight the distinction between the caregivers' perceived choice and their actual choice (see subtheme 2.7) by considering a wide range of contextual factors (see theme 1) if informal caregiving is to be effectively sustained. Incorporating the afore-mentioned factors in policy recommendations for practice is important when conducting assessments (e.g., when discharging people from hospital). Any caregiver assessment must recognise that the perception of choice, the actual choice and situational circumstances may change over time and thus should be revisited in a timely way.

The current meta-synthesis emphasises the importance of support for caregivers, consistent with a report investigating national policies for adult caregivers across Europe published by the European Commission (Bouget et al., 2016). Where in-home services were available most caregivers felt appreciative of them (calling them even a 'lifeline'), as they were positively related to motivations and willingness for caring, reduced their burden and enabled coping (Gerdner et al., 2007; Lee et al., 2019; Lewis et al., 1995; McDonnell & Ryan, 2014; Neufeld & Harrison, 1998; Öhman & Söderberg, 2004; Stajduhar et al., 2008) – similarly with regards to respite care and short breaks services (Russell, 2001; Sterritt & Pokorny, 1998; Tretteteig et al., 2017a; Tretteteig et al., 2017b). The other features of the developed caregiver support would comprise generous benefits (both to the care recipients and to the caregivers) and the flexible structure of the labour market (e.g., working hours, provision of short-term paid leave) (Boer & Plaisier, 2020; Bouget et al., 2016). It should be highlighted that the sustainability of caregiver motivations and willingness cannot be achieved by caregiver benefit provision alone. The absence of any employment and social policies had negative effects on motivations and willingness to care what was evidenced in caregivers' accounts pertaining to difficulties combining care responsibilities with employment or with competing familial roles (Albinsson & Strang, 2003; Alonso et al., 2018; Arpanantikul, 2018; Bryant & Lim, 2013; Han et al., 2008; Ho et al., 2003; Jones et al., 2002; Jones et al., 2003; Kao & Stuijbergen, 1999; Kim & Theis, 2000; Knight et al., 2016; Li et al., 2012; Ng et al., 2016; Sheu, 1997; Spitzer et al., 2003; Wallroth, 2016; Weinland, 2009). The importance of addressing broader societal factors (e.g., work conditions, education, social safety, addressing care recipient's illness stigma, housing) should also be stressed for the future of caregivers as these 'macro' factors are crucial in terms of the sustainability of care across the globe.

## Strengths and limitations

A strength of this review is its comprehensive nature: international evidence is reviewed using studies reported in one of four languages; no restrictions were applied to the care recipient's diagnosis or to the caregiver relationship type. Publication bias was addressed via an extensive search of additional sources. Inductive, grounded theory based thematic synthesis allowed the identification of various determinants of motivations and willingness to provide informal care. Most studies were judged to be of high methodological quality although some omitted important demographic details, and the balance in terms of nation of study of origin, ethnicity, gender, and illness was unequal making us less confident in the relevance of our findings for some sub-populations.

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## Author contributions

Conceptualisation: MZ & VM.

Data curation: MZ.

Data screening and extraction: MZ & EB.

Formal analysis: MZ conducted and led the analysis; EB supported the first stage of grounded theory-based thematic synthesis (axial coding). The development of descriptive and analytic themes was discussed with VM & DS altogether with interpretation of the literature.

Methodology: MZ & VM.

Supervision: VM & DS.

Validation: MZ & EB.

Visualisation: MZ.

Writing – original draft: MZ.

Writing – review & editing: MZ, VM & DS.

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## Data availability statement

All relevant data are within the manuscript and its supporting online supplementary files.

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