

Cultural and societal motivations for being informal caregivers: a qualitative systematic review and meta-synthesis

Zarzycki, Mikołaj; Morrison, Valerie; Bei, Eva; Seddon, Diane

Health Psychology Review

DOI:

<https://doi.org/10.1080/17437199.2022.2032259>

Published: 01/06/2023

Publisher's PDF, also known as Version of record

[Cyswllt i'r cyhoeddiad / Link to publication](#)

Dyfyniad o'r fersiwn a gyhoeddwyd / Citation for published version (APA):

Zarzycki, M., Morrison, V., Bei, E., & Seddon, D. (2023). Cultural and societal motivations for being informal caregivers: a qualitative systematic review and meta-synthesis. *Health Psychology Review*, 17(2), 247-276. <https://doi.org/10.1080/17437199.2022.2032259>

Hawliau Cyffredinol / General rights

Copyright and moral rights for the publications made accessible in the public portal are retained by the authors and/or other copyright owners and it is a condition of accessing publications that users recognise and abide by the legal requirements associated with these rights.

- Users may download and print one copy of any publication from the public portal for the purpose of private study or research.
- You may not further distribute the material or use it for any profit-making activity or commercial gain
- You may freely distribute the URL identifying the publication in the public portal ?

Take down policy

If you believe that this document breaches copyright please contact us providing details, and we will remove access to the work immediately and investigate your claim.



Cultural and societal motivations for being informal caregivers: a qualitative systematic review and meta-synthesis

Mikołaj Zarzycki, Val Morrison, Eva Bei & Diane Seddon

To cite this article: Mikołaj Zarzycki, Val Morrison, Eva Bei & Diane Seddon (2022): Cultural and societal motivations for being informal caregivers: a qualitative systematic review and meta-synthesis, Health Psychology Review, DOI: [10.1080/17437199.2022.2032259](https://doi.org/10.1080/17437199.2022.2032259)

To link to this article: <https://doi.org/10.1080/17437199.2022.2032259>



© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group



Published online: 09 Feb 2022.



[Submit your article to this journal](#)



Article views: 123



[View related articles](#)



[View Crossmark data](#)

Cultural and societal motivations for being informal caregivers: a qualitative systematic review and meta-synthesis

Mikołaj Zarzycki ^a, Val Morrison ^a, Eva Bei ^b and Diane Seddon ^c

^aSchool of Human & Behavioural Sciences, College of Human Sciences, Bangor University, Bangor, UK; ^bDepartment of Psychology, Faculty of Social Sciences, Bar-Ilan University, Ramat Gan, Israel; ^cSchool of Medical and Health Sciences, Bangor University, Bangor, UK

ABSTRACT

Informal caregiving constitutes the mainstay of a society's care supply. Motivations for caring and continuing to provide care are crucial to understanding the nature of caregiver experiences and their relationship with the person/people they support. This systematic review of qualitative evidence examines determinants of motivations and willingness to provide informal care. One hundred and five qualitative studies published before August 2019 and fitting the inclusion criteria were identified, 84 of them pertaining to cultural and societal motivations for caregiving. Grounded theory-based, thematic synthesis was conducted. Cultural and societal factors strongly underpinned motivations and willingness for informal caregiving. The main cultural motives for caregiving were cultural values and beliefs encompassing the ethnocultural context of the caregiving role, culture-specific norms, cultural and spiritual beliefs, illness beliefs and socialisation. Societal norms and perceived expectations, such as gendered roles, norms and expectations of caregiving, and perceptions of health and social care services further shaped caregiver motivations and willingness to provide care. These meta-synthesis findings contribute towards novel understandings about the cultural and societal aspects shaping informal care provision. These findings bear important implications for theory, research, policy and practice; all of which contributing to the issue of the sustainability of informal care from a 'macro' perspective.

ARTICLE HISTORY

Received 11 May 2021
Accepted 18 January 2022

KEYWORDS

Informal caregiving;
motivations to provide care;
willingness to provide care;
culture; society; values

Introduction

Becoming a caregiver is something that most people will experience during their lifetime (Lewis, 1997). Providing care and support presents a significant global challenge, especially for the most rapidly growing parts of the population, i.e., frail older people and adults living with chronic and acute health conditions. Increasing life expectancy and smaller family size (Bettio & Verashchagina, 2010; Börsch-Supan, 2019; Schwarzkopf et al., 2012) place considerable demands on formal care systems and also on informal caregivers. Whilst definitions of informal caregiving can vary across studies and across legislative, policy and practice contexts (Bauer & Sousa-Poza, 2015), it is generally defined as 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). It can be considered the mainstay of a society's care supply (Albertini et al., 2007; Stajduhar et al., 2010). In the UK alone, there are

CONTACT Mikołaj Zarzycki  m.zarzycki@bangor.ac.uk

 Supplemental data for this article can be accessed at <https://doi.org/10.1080/17437199.2022.2032259>.

© 2022 The Author(s). Published by Informa UK Limited, trading as Taylor & Francis Group
This is an Open Access article distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives License (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is properly cited, and is not altered, transformed, or built upon in any way.

approximately 8.8 million caregivers (Carers UK, 2019a) with 1.3 million of them providing more than 50 h of care per week (Carers UK, 2019b). The prevalence of informal caregiving varies across the world (Albertini et al., 2007; Carers UK, 2019a, 2019b; Lewis, 1997) but caregiver contribution to the sustainability of health and social care systems is significant. Despite this, we have limited understanding of the factors that underly, promote and maintain motivations and willingness to provide informal care (BurrIDGE et al., 2007; Parveen & Morrison, 2012; Parveen et al., 2011). Understanding motivations and willingness to provide care is important as it has implications for caregivers' and care recipients' well-being (BurrIDGE et al., 2007; Parveen & Morrison, 2012), and assessment and care planning processes that are in place to support caregiving relationships. It also has implications for the wider society – enhancing positive motivations to care and continue caring (whilst being careful not to make assumptions about willingness to care) is increasingly important given the ageing demographic, described above, societal expectations of community based, familial care provision and the potential costs to society of alternative care and support arrangements. Hence, it is important to understand why people provide informal care, that is, what motivates them and what determines continued caregiving.

As motivation is multifaceted (Kanfer et al., 2008) and multiply determined (Baker et al., 1988), different factors contributing to the influence on motivations should be considered. Motivations are 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). It follows, therefore, that identifying the factors underlying motives for providing (or not providing) care, exploring the interrelationships between different motives and considering the influence of these motivations on caregiver behaviour and outcomes will help in efforts to support and sustain caring relationships. Norms of perceived obligation towards family members, familism and ethnicity have previously been shown to have a predictive value for motivations and the exchange of informal care (Dykstra & Fokkema, 2012; Ikkink et al., 1999; Parveen et al., 2011, 2013, 2014; Silverstein et al., 2006). Caregiver motivations may impact significantly on outcomes for both caregivers and those they care for. This includes both positive and negative influences on caregiver health and wellbeing and the quality of the caregiving relationship (Greenwood & Smith, 2019; Quinn et al., 2010). However, as yet there is no synthesis presenting what underpins the motivations.

Alongside the concept of motivations to provide care, willingness to perform informal care tasks addresses more behavioural aspects of caregiving with current (actual) and future (hypothetical) orientations towards providing support for an individual (Abell, 2001; Zarzycki & Morrison, 2021). Whilst *motivations* can refer broadly to the reasons and drivers underlying, directing and maintaining caregiving behaviour (Ryan & Deci, 2000; Woolfolk, 2013), *willingness* to perform care typically addresses certain aspects of caregiver behaviour, for example, willingness to carry out specific emotional and personal care tasks (Abell, 2001; McDonnell et al., 1991). An individual may be motivated for various reasons 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).

BurrIDGE et al. (2007) in their systematic review of 17 studies focusing on cancer caregiving identified 4 groups of willingness to care indicators (demographic, physical, social and psychological – including emotions), providing the first synthesis of evidence pertaining to the role willingness to provide care plays in informal care. These indicators are noticeable in studies with other caregiving subpopulations and include basic demographic characteristics (e.g., gender, age, place of residence), family structure (e.g., number of siblings), family dynamics (e.g., attachment, communication style), religious affiliation (non-religious vs. religious), masculinity/femininity, and the care recipient's illness characteristics (e.g., their physical incapacity such as problems with mobility, their comorbidities) (BurrIDGE et al., 2007; Dykstra & Fokkema, 2012; Lieberman & Fisher, 1999; Wells & Johnson, 2001; Williams et al., 2014). BurrIDGE and colleagues (BurrIDGE et al., 2007) highlighted the potential impact willingness to provide care may have on caregiver outcomes, for example, reporting that when care is provided reluctantly it may result in a deterioration in the caring relationship. Similarly,

Camden et al. (2011) reported that those who were unwilling to provide care reported higher abusive behaviours towards the care recipient and their care recipient was more likely to be admitted to a nursing home. As societal demand for informal care grows (Hoffmann & Rodrigues, 2010; Kooiker et al., 2019; Pickard, 2015), it is important to understand the effect the determinants have on motivations and willingness to provide care, as these are likely to affect caregiver outcomes and behaviours (e.g., caregiver wellbeing, and their potential willingness to consider care home placement when perceived as necessary). *No synthesis* of qualitative evidence on motivations and willingness to provide informal care has been completed outside the cancer and dementia caregiving population.

Looking at levels of influences in understanding human beliefs and behaviour, there are potential 'macro' and individual factors that may in the current context influence motivations and willingness to care. This paper sets to identify these 'macro' determinants in the population of adult caregivers providing care to adult care recipients, specifically *potential* cultural and societal influences on motivations and willingness for caring.

Models of health and illness vary across and within cultures and societies because of the political, economic and cultural climates e.g., social inequality, the structure of economic opportunities and labour needs, and cultural beliefs (Baca Zinn & Wells, 2000; Chalmers, 1996). 'Macro' factors, which include cultural and societal influences, are likely to impact models of care, caregiving expectations and behaviour, for instance, why and how people provide informal care.

Culture can be considered 'a learned system of symbols with shared values, meanings, and behavioural norms' (Kavanagh & Kennedy, 1992, p. 12), an implicit 'guiding force' regulating how individuals respond to demands they encounter and as such it may influence caregiving motivations (Dilworth-Anderson et al., 2005). The anthropologist Geertz defines culture as 'a set of control mechanisms – plans, recipes, rules, constructions, what computer engineers call programmes for the governing of behaviour' (Geertz, 1973, p. 44). The control mechanisms are assimilated and internalised through an ongoing process of socialisation, yet they can be imperfectly reflected in behaviour because of conflicting value priorities, variations in cognitive interpretations or resistance to the control imposed by the cultural rules (Geertz, 1973). Situational circumstances may limit people's ability to model the cultural ideal (e.g., people may feel less willing to provide care for an elderly family member facing chronic ill health if they are employed, or if they have competing demands of child care).

The wider societal context may also shape caregiving motivations and willingness. For example, the welfare and support systems, and the policies underpinning these, can shape perceptions of informal care and what it may constitute (Bambra, 2005; Cash et al., 2013; Fawcett, 2014). Studies have demonstrated that the fragmented nature of social care services in countries such as in Australia and the UK, and the associated emphasis on competition and on short-term funding make it difficult for service providers to be responsive to the needs of informal caregivers and care recipients, which may influence caregiving burden and motivations (Al-Janabi et al., 2018; Del-Pino-Casado et al., 2011; Hughes & Heycox, 2020; Khalaila & Litwin, 2012; Leonard & Johansson, 2008). Some health and social care policies are based on the premise that family members and friends will undertake the caregiving role and will provide the majority of care (Sims-Gould & Martin-Matthews, 2008). As such, these policies affirm societal/cultural norms of familism and traditional caregiving roles, which include, for example, gender-specific norms of caregiving, which may (or may not) affect motivations and willingness to provide care. This systematic review of qualitative evidence seeks to identify these factors and explore their influence in order to further current understanding.

The increasingly complex care needs of the population, coupled with the predicted decline in the availability of informal caregivers are leading to a 'Care Gap' (Kooiker et al., 2019; Pickard, 2015) that will present significant challenges to the future sustainability of global healthcare and social care systems. Therefore, it is important to identify any cultural or societal factors that influence motivations and willingness to provide care. No previous systematic review has explored 'macro' determinants of caregiving motivations and willingness to such a broad extent. We propose that these

factors, and the consequent improved understanding of how they act upon individual cognition, expectation, motivations, and ultimately caregiving behaviour and outcomes, will help expand both the theoretical models we have around predicting caregiving processes and its outcomes, but will also offer useful information to those developing interventions with a view to mitigating against negative caregiver experience.

Review aims

This systematic review aimed to further understanding of the influences shaping motivations and willingness to provide care and to achieve the following objectives:

- (a) Identify existing literature on determinants of motivations to provide care and willingness to care within the context of informal caregiving.
- (b) Screen the literature and extract empirical findings in accordance with predefined criteria.
- (c) Critically appraise and synthesise the existing research findings.
- (d) Explore the factors underlying caregivers' motivations and willingness to provide care.
- (e) Explore whether any differences exist among caregivers when describing their motivations and willingness to provide care.
- (f) 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). Originally, a mixed-method systematic review was planned. Due to the large number of eligible studies and the need to present the findings in an efficient and robust way, the decision was made by the review team to present the qualitative meta-synthesis findings separately from the quantitative findings. This was in line with the strategy for data synthesis described in the PROSPERO protocol, i.e., that separate forms of syntheses for quantitative and qualitative studies would be conducted.

Design

A qualitative review using a configurative perspective was completed, following Evidence for Policy and Practice Information and Coordinating Centre (EPPI-Centre) guidance (EPPI-Centre, 2010; Gough et al., 2017). Configurative aspects examined determinants of motivations for providing care and willingness to provide care following a review and meta-synthesis of the results of qualitative studies.

This paper focusses on cultural and societal influences (i.e., 'macro' determinants) on motivations and willingness to provide care and integrates results from several different but inter-linked qualitative studies with interpretive, rather than aggregative intent (Booth, 2016). A separate paper presents a synthesis of qualitative findings relating to 'individualistic' (personal and relational) 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, providing care to adult (aged 18 years and over) care recipients. The subpopulation of parent caregivers of young children is typically distinguished in research from the population of

informal caregivers providing care to adults. Parent caregivers were not included in this systematic review (Revenson et al., 2016). Informal caregiving was defined broadly as providing usually unpaid physical, practical and psychological support for a family member or friend with a chronic illness, disability, or other long-lasting health and care needs (Bridges, 1995; Revenson et al., 2016).

Phenomena of interest (concepts). Studies exploring motivations and/or 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.

Inclusion criteria. Empirical qualitative research, including original research, case studies, dissertations, theses (Gough et al., 2017). Studies reported in English, French, Polish or Russian languages were to be included as these met the authors' language capabilities. No restrictions were applied to caregiver relationship type, e.g., spouse/non spouse, gender, care recipient's age, gender or care recipient's diagnosis.

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 amended from those used in a previous systematic review of the impact of motivations on caregiver outcomes (Quinn et al., 2010) to explore the factors that *influence* motivations and willingness to provide care. Additional scoping searches identified that the search terms used to describe 'caregivers', 'motivations to provide care' and 'willingness to provide care' were insufficiently sensitive (defined as identification of as much evidence as possible; Gough et al., 2017) to capture all papers that related to these terms with studies wrongly excluded because of their poor indexing. Given the need to include all relevant papers and sustain a balance between sensitivity and specificity, terms relating to the 'caregiver' (such as for example 'spouse', 'relative' or 'family'), 'motivations to provide care' and 'willingness to provide care' (such as for example 'obligation' or 'motives') were also used even though this reduced specificity (defined as precision of the search; Gough et al., 2017).

The searches were conducted only in English, with English spellings of words, but any papers in the English, French, Polish and Russian languages were screened if returned through the searches. The truncation (*) was used when appropriate and Boolean search terms AND/OR were used to connect search terms.

Information sources

The searches examined papers published up until August 2019 using the following databases: MEDLINE via EBSCO, PsychInfo, Applied Social Sciences Index and Abstracts, CINAHL, Cochrane Library, Web of Science. The search strategy was designed in CINAHL and then translated to the appropriate MESH/thesaurus terms and formats for the other databases. This was an iterative process between and within databases, to ensure a balance between specificity and sensitivity.

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. Duplicates were removed before reviewing against the eligibility criteria.

To ensure that the search was comprehensive and inclusive, and to reduce the effect of publication bias, a search of additional sources including unpublished and grey literature, general searches (i.e., 'Google Scholar') and PhD theses and dissertations (EPPI-Centre, 2010) was conducted. Contacting experts (four experts in the field and two caregiver-specific organisations) and hand searching (i.e., conference proceedings and retrospective reference list checking) were carried out.

Selection process

Titles and abstracts were screened by the principal researcher (MZ) according to the inclusion and exclusion criteria. Following this, retrieval and review of potentially eligible full-text papers were conducted by two reviewers (MZ, EB) with a sample of 20% retrieved and screened against the eligibility criteria to assess inter-rater agreement. Disagreements were managed in accordance with a pre-agreed protocol. One disagreement occurred concerning a low-quality paper (Asahara et al., 2002) which contained two sub-samples of participants – only one of which met the inclusion criteria (of informal caregivers) – the reviewers agreed to include only the findings relating to this sub-sample.

Data extraction

Standardised, comprehensive data extraction forms were designed for the purposes of the descriptive (systematic) map and synthesis, and completed for each included study. Data extraction included information on: the country of study; study aims; participants; research methods; and main constructs from the conceptual framework (i.e., the content of the interview guide).

Qualitative and mixed-method data extraction forms were applied based on guidance published by Cochrane, the Joanna Briggs Institute and the EPPI Centre (EPPI-Centre, 2010; Gough et al., 2017; Institute, 2011; Noyes & Lewin, 2011) and were piloted to ensure their suitability. The data extraction process was independently checked for accuracy by EB employing double coding on 20% of included studies. There was a high rate of coding agreement thus single reviewer coding was conducted on the remaining studies.

Quality and relevance appraisal (QRA)

Quality and relevance appraisals (QRA) were conducted by the two reviewers (MZ, EB) on 20% of the included studies using quality assessment tools and a high rate of agreement achieved. Reviewers (MZ, EB) scored 200 items and agreed in 188 cases (94%) which provides substantial inter-rater reliability ($\kappa = .70$). Solo critical appraisal was applied to the remaining studies.

Each included study was next dual-assessed according to the three '*Dimensions of Difference of Evidence Claims*' (Gough et al., 2017):

- (1) *the review methods* – the methodological standard of the review was first assessed for appropriateness using the PRISMA statement (see online S1 Supplementary File) and then the suitability of method and relevance to the review aims was appraised by the review team (MZ, EB, VM, DS).
- (2) *the methods of the included studies* were assessed with the *Weight of Evidence Framework* (Gough et al., 2017) which critically appraised methodological standards, suitability and relevance, specifically the:
 - quality of execution of the study ('study soundness'),
 - appropriateness of the study design and analysis for answering the review question,
 - relevance of the study to the review.

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 and the relevance of the individual studies were judged in accordance with the review aims and awarded an assessment of high, medium or low (see online S1 Supplementary File). Based on this part of QRA (CASP, 2014; Gough et al., 2017) reviewers decided that where qualitative studies with low methodological quality ($N=4$) still met the requirements of the data synthesis they would be included. Additionally, quality and relevance of the studies were described (Gough et al., 2017).

(3) Thirdly, *the quality of the evidence produced* and the confidence in each of the themes arising from the meta-synthesis were assessed using the GRADE-CERQual approach (Lewin et al., 2018) based on consideration of: (a) methodological limitations of the studies contributing to each analytic theme; (b) coherence of each analytic theme; (c) adequacy of data supporting each theme; (d) relevance of the data to the review question. The reviewers considered these four components for the subset of studies contributing to each of the main emerging analytic themes in order to generate a GRADE-CERQual Qualitative Evidence Profile in a form of a Summary of Qualitative Findings table (Lewin et al., 2018) (see online S2 Supplementary File).

The lead reviewer (MZ) assessed confidence in each analytic theme for specific study characteristics, including study design, gender, ethnicity, care recipient's illness, the caregiver – care recipient relationship, geographic continent and the socioeconomic level of development of the countries represented (List of Developing Countries, 2018; see online S2 Supplementary File). 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 caregiver age and duration of care provision across each analytic theme as these characteristics were inconsistently reported. Confidence in findings when removing 4 studies with low methodological quality was assessed using sensitivity analysis.

Data synthesis

The review synthesis comprised of two stages. Firstly, systematic mapping of all identified studies and their characteristics was conducted using the EPPI-Centre core keywording strategy (EPPI-Centre SSRU, EPPI-Centre, 2002) to code studies according to demographic data and review-specific data before producing the descriptive map of all studies meeting our inclusion criteria. Second, in-depth review was carried out using inductive grounded theory-based, thematic synthesis to synthesise study findings and assess concepts across included papers, i.e., thematic synthesis was directed by the grounded-theory approach according to guidance (Braun & Clarke, 2006; Charmaz, 2006; Gough et al., 2017; Thomas & Harden, 2008). Applying a grounded theory approach to synthesis deepened 'immersion' within the data through application of selected analytic techniques (i.e., constant comparisons, coding principles and memoing), thus adding additional depth and richness to the generation of the themes (e.g., further clarifying the definition and scope of each theme).

The inductive grounded theory-based and thematic synthesis approach consisted of three stages (overlapping analytical procedures described below):

- (1) coding text (preliminary synthesis) as (axial) codes (or underpinning/emergent themes);
- (2) organising the themes from (1) into 'descriptive themes' – either organising themes into overarching themes or using other ways (e.g., conceptual mind mapping) to articulate the relationships between conceptually similar themes;
- (3) 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 conducted in NVivo 12 Pro; two reviewers (MZ/EB) coded the first twenty studies and then a single reviewer (MZ) coded a proportion of all the remaining studies. Preliminary

(axial) coding was discussed among the full review group to identify emergent themes and support the development of descriptive themes.

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.

One reviewer (MZ) worked on developing descriptive themes. The process involved re-organising the study data and (axial) codes and using a constant comparative method to record notes regarding emergent themes and discuss both associations and exceptions to these themes with the review team.

During synthesis, exceptions were explored to see if they could be explained by attributes of the study population, such as gender or ethnicity. After descriptive subthemes were identified and described, they were assessed in relation to preselected study characteristics. If characteristics were adequately reported, their contribution was assessed across each analytic theme. The assessment of analytic themes and descriptive subthemes by selected study characteristics in relation to the findings is presented in an online S2 Supplementary File.

Findings

Search results

The PRISMA diagram summarises the search flow (Figure 1). Electronic searches identified a total of 9793 papers before duplicate removal. After duplicate removal ($N=4141$) as well as titles and abstracts screening of the remaining 5652 articles, this systematic review, after the exclusions

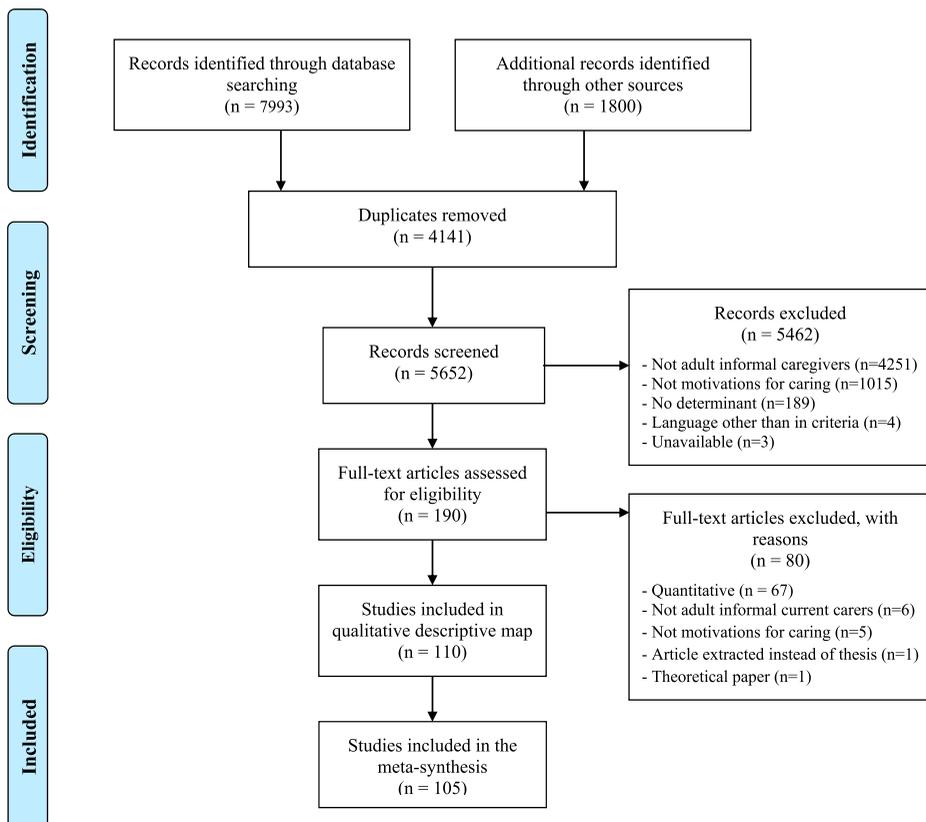


Figure 1. PRISMA flow chart of included studies.

($N = 5462$), identified 190 full-text records (from databases and additional searches screened) 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 provides the main reasons for exclusion.

Characteristics of included studies

The characteristics of the included studies are presented below with further detail presented in online S2 Supplementary File.

Most papers included were reported in the English language ($N = 109$). No articles in Russian were returned during the search; articles in French ($N = 18$) identified at the stage of primary screening were deemed ineligible; two studies described in Polish were returned in the search, one did not conform to eligibility criteria at the stage of primary screening, the other one (Piotrowska, 2015) was included in the systematic map, but was ineligible for the meta-synthesis as there were significant limitations in the analysis of data and the clear statement of findings.

Setting. All continents were represented: Asia ($N = 23$),¹ Middle East ($N = 3$) (Dumit et al., 2015; Kuşçu et al., 2009; Leichtentritt et al., 2004), Africa ($N = 6$),² Europe ($N = 22$),³ Australia and Oceania ($N = 4$) (Bryant & Lim, 2013; Cahill, 1999; Cash et al., 2013; Opie, 1994); North America ($N = 49$),⁴ South America ($N = 1$) (Almeida et al., 2018). This totals 108 studies as 3 studies (Harris & Long, 1999; Sung, 1994; Yamamoto & Wallhagen, 1997) which focused on cross-cultural comparisons were conducted across two different continents (e.g., subsamples both from North America and East Asia). Twenty studies were conducted in what is considered a developing country.⁵

Participants. Two thousand five hundred sixty five caregivers participated in the included studies with 77% being female ($N = 1986$) and 23% male ($N = 579$).

Caregiver reported age ranged from 16 to 91 years. However, in five studies age was indicated by the age of the youngest person, e.g., 23+⁶ and three studies concerned older caregivers exclusively (age above 64 without the specification of an upper age limit) (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.⁷ In 79 (75%), studies ethnicity was divided into broad sub-categories: mostly Caucasian ethnicity ($N = 25$);⁸ Asian ethnicity ($N = 36$);⁹ non-Caucasian American ethnicity ($N = 10$);¹⁰ Black African ethnicity ($N = 6$).¹¹ In a minority of studies ($N = 13$, 12%), ethnicity was either not reported/inconsistently reported (11) or inapplicable (2 documentary studies).¹²

Six studies (6%) did not report the type of caregiver-recipient relationship,¹³ 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;¹⁴ 11 studies (10%) were with mainly (at least 90%) spousal/partner caregivers;¹⁵ 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/domestic partnership caregivers ($N = 540$, 27%). The remaining 12% ($N = 247$) of caregivers comprised other relatives or non-relatives providing informal care.

In 23 studies (22%), the care recipient's health condition was not specified¹⁶ whilst 30 (28%) included various condition types within the study sample. Fifty-two (50%) studies included a single diagnosis: dementia ($N = 36$, 34%),¹⁷ cancer ($N = 7$, 7%),¹⁸ cardiac diseases ($N = 3$, 3%) (Alonso et al., 2018; Dumit et al., 2015; Holroyd, 2003), strokes ($N = 5$, 5%)¹⁹ and multiple sclerosis ($N = 1$, 1%) (Boeije et al., 2003).

Study design. Ninety six (91%) of the 105 synthesised studies were qualitative in design with further 9 mixed method studies containing qualitative data which was reported separately ($N = 9$, 9%).²⁰ Of these 16 (15%) employed a longitudinal study design.²¹ Data collection methods included: open or semi-structured individual or group interviews, ethnographic observation, or questionnaires

with open-ended questions. Studies used a range of grounded theoretical, narrative, phenomenological, hermeneutic, framework, ethnographic, descriptive or interpretive enquiry approaches to explore and analyse the data.

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,²² 44 (42%) were judged to be moderate,²³ 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 other 5 studies²⁴ 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 or continue to provide care were identified.

Five broad analytic themes were identified of which two are addressed in this paper:

- (1) Cultural values and beliefs
- (2) Societal norms and perceived expectations

These two analytic themes were identified in 84 studies of the 105 that were included in the whole systematic review, i.e., 21 papers did not provide data for the present synthesis.

The confidence in each of these analytic themes is summarised in online S2 Supplementary File. Removing studies with low methodological quality did not influence this confidence. However, there are minor/moderate concerns regarding data adequacy and relevance for some subpopulations and continents, which reduced the confidence in findings for: male caregivers; caregivers with Black African and Arab ethnic origins; reported illnesses (other than dementia); and the following locations Australia and Oceania, South America and Middle East.

Analytic themes, descriptive themes and axial codes are summarised in online S2 Supplementary File. The analytic themes and their subthemes (in bold) are presented, with Table 1 presenting a selection of illustrative quotes for each subtheme. An online supplementary file presents the findings more fully with overinclusive supporting quotes – see online S2 Supplementary File.

Theme 1: cultural values and beliefs

This analytic theme included five subthemes: cultural-specific norms of providing care; cultural socialisation; spirituality and religion; acculturation; and cultural aspects of illness beliefs.

Cultural-specific norms of providing care. Cultural-specific norms were grounded in cultural values and social beliefs about care provision in families and/or communities.²⁵ For example, a Confucian-inspired notion of filial piety was regarded as the fundamental principle in Asian (e.g., Korean, Chinese, Thai, Taiwanese) family life and enshrined in law in some cases (e.g., in The Korean Civil Act 1958). Filial piety was understood as a traditional and current practice through which older people are respected in the family unit and the wider society, and it was related to mutual exchanges and understandings shared between generations.²⁶

Cross-cultural studies, such as Harris and Long (1999), gave insight into the significance of cultural norms reporting that for Japanese male caregivers, as compared to American male caregivers, birth order and obligation to their parent were significant in motivating individuals to care and to continue caring (eldest son and/or his wife, the daughter-in-law). Cultural and social expectedness of caregiving was also informed by a 'position to take care of the elderly (*mirutachiba*)' (Wallhagen & Yamamoto-Mitani, 2006). Similar to the Japanese data, a study within Turkish and Moroccan

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

Analytic theme	Descriptive subtheme	Illustrative quote
1. Cultural values and beliefs	1.1 Cultural-specific norms of providing care	It's because I married the first son ... I had the idea that one day I had to take care of his mother ... (Yamamoto & Wallhagen, 1997, p. 169)
	1.2 Socialisation	So, I've always seen the way mothers, the females take care of the family ... So, I could see a lot of the nurturing was done by my mom and my grandma. So, it has carried down. (McDermott & Mendez-Luck, 2018, p. 7)
	1.3 Spirituality and religion	I also have a chance to do good things and save my place in heaven doing this job. (Hinton et al., 2008, p. 679)
	1.4 Acculturation	So, the daughter-in-law, according to the Vietnamese tradition, has a greater responsibility towards the husband's family than her own. But the present time, having come to Canada, it seems as though the responsibility is half for the husband's family and half for the wife's family. (Donovan & Williams, 2015, p. 83)
	1.5 Cultural aspects of illness beliefs	It's a 'loss of face' to have a husband with dementia, especially when he is so young. I will not seek help from others because they will look down on me. I felt inferior to others. (Pang & Lee, 2019, p. 1620)
2. Societal norms and perceived expectations	2.1 Seeking social recognition and conforming to societal pressure	I think you have to take care of your ill parents or in-laws at home in order to save face ... I think it is the Korean way that you don't send them to a nursing home. (Kong et al., 2010, p. 322)
	2.2 Gender-specific roles	I think that as a woman and a daughter it is very important to care for your mother. This kind of care should not be questioned as it is born within you, and others expect it of you. (Holroyd, 2001, p. 1129)
	2.3 Social policy intent and assumptions underpinning this	I needed a [financial welfare] compensation, that was the long and short of it. I couldn't really survive without it. (Kietzman et al., 2013, p. 532)
	2.4 Perceived limitations to formal support provision and services	The most important thing I want to say is lots of agency and professional people don't understand our culture, don't understand our faith, and the most important thing is our voice not being heard.' (Parveen et al., 2011, p. 869)
	2.5 Avoiding admission to a care home	We have to take care of our own. No one's going to take care of my sister like I am.' (Nkongho & Archbold, 1995, p. 120)

communities found that family care was primarily the responsibility of the eldest daughter or the wife of the eldest son (van Wezel et al., 2016); likewise amongst the Surinamese Creole community an eldest daughter would be expected to take care of her parents (van Wezel et al., 2016). In other studies, patrilineal and primogeniture norms were ingrained in caregiver socialisation – women knew they may need to provide informal care if they married the first son (Wallhagen & Yamamoto-Mitani, 2006; Yamamoto & Wallhagen, 1997). The caregiving duty was reported as being taken for granted within wider traditional Asian culture (Lee et al., 2019).

In Thailand, daughters were expected to bring their husbands into their family system and cultivate their parents' land and there was an expectation that the youngest daughter would remain in the household (even after her marriage) and care for her parents (Sasat, 1998). In Nigeria the norm of caregiving for a relative was also deeply enshrined (Muoghalu & Jegede, 2010).

Caregiving can be shared. This was seen in a study of Arab and Muslim caregivers in Israel where responsibilities for care were divided among several people in the family, regardless of gender or birth order (Leichtentritt et al., 2004).

The implicit value system embedded in the cultural context determined motivations for caregiving, where caregiving was seen as natural, in many cases central to identity.²⁷ Cultural values comprised a distal, contextual factor in motivations to provide care²⁸ and included various examples²⁹ such as the aforementioned traditional value of filial piety or the value of *marianismo* ('self-sacrificing mother') seen in the Mexican culture (Mendez-Luck & Anthony, 2016). Cultural values instilled in participants constituted the basis for a sense of obligation to provide care and were shaped during

specific socialisation (Ho et al., 2003) – this links to the *cultural socialisation* theme (see below). The value system upheld people's common concern for filial piety, commitment to the caregiving role, caregiving motivation and affirmed the validity of traditional cultural caregiving practices (Jones et al., 2003; Park, 2015) even when facing a new cultural context (e.g., Chinese immigrants living and providing care in the USA or providing distant care to their relatives living in China) (Han et al., 2008; Hsueh et al., 2008; Jones et al., 2002; Kim, 2009; Kong et al., 2010).

Cultural socialisation. This subtheme addresses the incorporation of cultural values promoting informal care provision through exposure to caregiving model(s). A process of behavioural modelling was embedded in an individual's upbringing,³⁰ highlighting personal socialisation and the early creation of a sense of responsibility, a preparation for the role (Globerman, 1996). Socialisation played a significant role both in motivations to provide care and willingness to continue the role as seen in the accounts of Asian caregivers but also amongst European, American and Canadian caregivers.³¹

Incorporation of Asian (e.g., Korean, Chinese, Japanese) values within socialisation encouraged the development of filial responsibility from an early age. The value placed on filial piety was conveyed to people through various social processes, i.e., in education, family participatory teaching, informal demonstration of caring tasks being carried out by other family members, oral transmissions by various media (e.g., national media, portrayals in TV and radio) and rituals from and for the community (e.g., The Filial Piety Prize awarded by the Ministry of Health and Social Affairs of the Korean government) entrusted with the task of maintaining cultural identity (i.e., an individual's identity as a member of a cultural group). Caregiving expectations were operationalised through the exposure to these experiences (Jones et al., 2002; Park, 2015; Sheu, 1997; Wallhagen & Yamamoto-Mitani, 2006) thus for many adopting the caregiver role was not unexpected (Wallhagen & Yamamoto-Mitani, 2006).

The caregiving role as modelled and witnessed within one's family influenced individual caregiving motivations (Jones et al., 2002; Leichtentritt et al., 2004; McDermott & Mendez-Luck, 2018; Murphy, 2005; Qiu et al., 2018). Cultural norms governing caregiving conduct within a given society were deeply internalised and self-identification with the caregiver role was, therefore, not unexpected with individuals describing caregiving as arising 'naturally' without conscious thought (Wallhagen & Yamamoto-Mitani, 2006). It was a learned process from continued observation of close relatives' caregiving behaviours.

The findings may also be related to dimensions of individualism-collectivism, described particularly within cross-cultural psychology (Sims-Gould & Martin-Matthews, 2008), where individualistic cultures are characterised by a focus on individual needs and relative detachment from relationships and communities whereas collectivist cultures are defined by the importance of relationships, roles and status within a social system. Variation in individuals' upbringing was also seen to be influential. For example, whilst America and Sweden are typically characterised by individualistic cultures, for some carers their personal upbringing resembled more collectivist caregiving models which shaped their future caregiver commitment (Sterritt & Pokorny, 1998; Wallroth, 2016).

Spirituality and religion. Many studies reported that religious beliefs and values, where present, constituted an important motivating factor initiating or maintaining the motivation for caregiving.³² Various religious or spiritual teachings were represented, predominantly Confucian, Buddhist or Christian thoughts.³³

The belief in the situation having arisen from God's will was a significant motivation to provide care and to continue care (Alonso et al., 2018; Hanyok et al., 2009; Jones et al., 2002; Mahilall, 2006; Murphy, 2005). A belief in karma (destiny/fate) was also reflected in caregiver accounts: the repayment of debts in the current life through caregiving (Hinton et al., 2008; Hsu & Shyu, 2003; Kao & Stuijbergen, 1999; Sasat, 1998; Sheu, 1997).

Acculturation. The processes of adjusting to a new culture were described in several studies³⁴ including where Asian people had emigrated to North America (Han et al., 2008; Hsueh et al., 2008; Jones et al., 2002; Kim, 2009; Kong et al., 2010). This evidence suggested that whilst pre-existing values remained an important source of motivation and willingness to provide care, there was a reported shift from 'cultural certainties' to 'important beliefs, norms and emotions' as the 'certainties' were thought to have been destabilised (Bryant & Lim, 2013). Accepting new cultural values did not mean discarding old ones and preserving old cultural values did not mean rejecting new ones (Donovan & Williams, 2015; Hsueh et al., 2008; Jones et al., 2002; Kong et al., 2010). However, balancing both created dilemmas and tensions for some families. Whilst pre-existing values still motivated individuals to provide care, an understanding of informal care provision in the new culture/country needed renegotiation and restructuring; for example, some caregivers found themselves able to transcend traditional cultural values of filial piety by engaging formal care services to help support them in the provision of care (Han et al., 2008; Hsueh et al., 2008; Kim, 2009; Kodwo-Nyameazea & Nguyen, 2008). Coexisting cultural norms and values were evidenced in the caregiver accounts, e.g., an influence of Canadian liberal culture and Vietnamese culture (Han et al., 2008).

Cultural aspects of illness beliefs. The cultural representations of certain health conditions, i.e., lay models of illness (Leventhal et al., 2003), were found to influence motivations and willingness to provide informal care, for example, the social stigma attached to dementia in China (EPPI-Centre SSRU, EPPI-Centre, 2002) or the views of dementia contagiousness held in Pakistan (Noyes & Lewin, 2011). Such social beliefs resulted in familial and social isolation of some caregivers, i.e., stigmatisation (and fears of further stigmatisation) or fears of contagion and a consequent lack of support were experienced by caregivers as painful but at the same time motivating in providing care (Lauritzen et al., 2019; Leichtentritt et al., 2004; Park, 2012).

Theme 2: societal norms and perceived expectations

The impact of caregiving norms and expectations on the caregiving role and experience was seen at a personal (individual) and a collective (public) level. Descriptive subthemes were identified within two broader groupings: (a) roles, norms and expectations specifying what is societally normative in terms of caregiving and (b) social policy intent and the underpinning assumptions.

Seeking social recognition and conforming to societal pressure. The need for social recognition and praise to create and/or sustain a picture of being a 'good carer' was evident (Kodwo-Nyameazea & Nguyen, 2008; Mahilall, 2006; Pang & Lee, 2019; Sheu, 1997). Appreciation shown towards caregivers by other members of society (including siblings, the care recipient, the wider community) was an important motivating factor that enhanced willingness to continue to care (Dunér, 2010; Erickson, 2002; Kietzman et al., 2013; van Wezel et al., 2016).

Caregiving responsibilities were upheld due to the importance attached to receiving positive affirmation and to be seen as acting in a socially acceptable way. Perceived pressure from others (friends, loved ones and professional healthcare staff) to provide care left little freedom of choice: deviation from societal expectations had anticipated negative consequences such as less respect and/or strained familial or community relationships.³⁵

Gender-specific roles. Gendered social and cultural norms and expectations of informal care provision were highlighted in caregiver accounts. In many countries, caregiving has traditionally been considered a women's responsibility, arising from the socialisation process and constituting a social norm.³⁶ Gendered social norms and expectations typically focused on women as 'boys are unlikely to help' (Wiles, 2002, p. 302) within female-centred care networks (Holroyd, 2001) which, depending on the specific sociocultural context, included daughters, daughters-in-law and wives; sometimes in a hierarchy (e.g., wives, daughters, daughters-in-law).

The belief that caregiving is 'women's work' was shared by both women and men (Aronson, 1992; Spitzer et al., 2003; Wallroth, 2016). A perception of women's 'natural' affinity for the role appeared ingrained within some cultural values.

In two studies of male caregivers, the view was expressed that the gender of the care provider bore less importance than the nature of the caregiving task, i.e., that men felt more competent in performing particular aspects of care, e.g., practical care tasks (Wallroth, 2016; Weinland, 2009).

Social policy intent and underpinning assumptions. Assumptions that family/informal caregivers will provide care underpins social policy and legislation in some countries (Bettio & Verashchagina, 2010) with policy intent driven largely by public spending considerations (Cash et al., 2013). Such assumptions leave no place for those who may not want to care (Cash et al., 2013).

The rhetoric expressed in one study (Muoghalu & Jegede, 2010) was that supporting caregivers (e.g., through social benefits) helps sustain motivations to provide care and reduce pressure on publicly funded (formal) services. Where policies such as this are not in place, motivations to care may be undermined. Policies that would promote and maintain caregiver well-being were not mentioned. Given the above, it was suggested that caregivers' motivations and well-being are of value if they reduce financial burdens for the state. In some countries, for example Korea, as mentioned above, there is a lawful obligation for adult children to provide care for their parents (The Korean Civil Act, Civil Code, enacted on February 22, 1958) (Park, 2015), leaving no policy consideration of the ability or willingness of family to meet the financial costs of caregiving.

The financial costs of providing care to someone in their own home/caregivers' home were compared by some to meeting the costs of a care home or of formal support (in one's own home) with caregivers expressing financial worries regarding these costs (Kao & Stuifbergen, 1999; Qiu et al., 2018).

Only in one study (Kietzman et al., 2013) was monetary incentive (i.e., US governmental payments/welfare benefits) considered when exploring motivations to provide care. It seemed that the benefits played a secondary role in motivation for most who 'didn't do it for money', but for many it was helpful, and for others it was essential.

Perceived limitations to formal service provision. Perceiving barriers to accessing formal services or considering them as ineffective in addressing caregiver and care recipients' needs (Hsu & Shyu, 2003; Zarzycki & Morrison, 2021) led to a perceived lack of alternative care options and choice for many caregivers. This was key in motivating caregivers to provide care themselves.³⁷ For some, language (cultural) barriers decreased their access to and utilisation of formal provision, which in turn motivated them to provide care (Donovan & Williams, 2015; Hsueh et al., 2008; Kim, 2009).

Lack of knowledge of formal support (Almeida et al., 2018; Qiu et al., 2018; Vellone et al., 2002) comprised both a limitation and at the same time a motivator for caregiving oneself. Even when knowledge of care services existed (e.g., of day care, respite or residential options), pressure on these services meant that there was not always availability (Guberman et al., 1992; Kodwo-Nyameazea & Nguyen, 2008).

Lack of respite care services was considered as exacerbating the caregiver sense of burden and, therefore, the quality of the informal care provision, i.e., some caregivers expressed the expectation that were there availability of respite care, it would help them to cope with their caring commitments by giving them time out to pursue other activities, refresh and remotivate (Leichtentritt et al., 2004; Lewis et al., 1995). However, the synthesised data did not mention how the quality or timing of respite care provision could moderate caregivers' experience and expectations around this form of support services in relation to caring motivations and willingness.

Avoiding admission to a care home. Negative perceptions of care homes (residential and nursing) were present in many caregivers' accounts, with placement seen as inappropriate for their care recipient either due to cultural, familial and individual values, a lack of confidence in the quality of provision or fear of condemnation from their community. Caregivers were motivated to provide and continue to care as a means of preventing or delaying care home admission.³⁸

Anti-institutional feelings may be underpinned by the aforementioned social norms of family care, with assumptions that family care is a 'better' option, being more loving, dignified, individualised and person-centred and offering more security and recognition for the care recipient.³⁹

Maintaining a familiar environment, wanting to maintain the care recipient's dignity and privacy as well as fears of others not providing the same quality care motivated the provision and continued provision of care.⁴⁰

Discussion

Summary of findings

This systematic review comes at a critical time when society faces the challenges of an ageing population and a rising prevalence of chronic conditions and associated care needs (Carers UK, 2019a). Informal care is crucial for the sustainability of health and social care systems globally. Understanding 'why' caregivers take on and importantly, continue their role, will inform future policy and practice development.

This meta-synthesis brought together studies from a wide range of countries and cultures, covering over two decades, and highlights a growing interest in understanding the cultural and societal underpinnings of caregivers' motivations and willingness to provide care, i.e., 'macro' determinants of caregiving motivations and willingness. We identified and critically appraised 84 qualitative studies that reported cultural and societal motivations for caregiving. This enabled a comprehensive assessment by study characteristics and exploration of similarities and differences amongst caregivers' motivations. In further sections, we consider the implications for theory development, future research, and future policy and practice development.

Key factors impacting caregivers' motivation and willingness to provide care arising from this systematic review included:

- (1) cultural values and beliefs encompassing the ethnocultural context of the caregiving role; cultural and spiritual beliefs; norms, values and socialisation, specifically highlighting how these regulated caring obligations;
- (2) societal norms and perceived expectations such as gendered roles, norms and expectations of caregiving as well as perceptions of formal services and the policy underpinning these.

Caregivers had multiple motivations and were rarely driven by one motivation alone.

Authors did not distinguish between the concepts of motivations and willingness to provide informal care, as these were not distinguishable in the caregivers' accounts. Although there are conceptual overlaps between these constructs, it should be highlighted that motivations to provide care seem to be in our view a more primary construct than willingness to provide care – for example, negative views of care homes could underpin why a person is motivated to provide care in the first place, and at the same time influence willingness to continue providing care. This systematic review casts some light on the interrelationships between these concepts as compared to existing quantitative research, in which these constructs are treated independently (Abell, 2001; Lyonette & Yardley, 2003; McDonnell et al., 1991; Parveen et al., 2013; Parveen et al., 2014). This warrants a need for future theoretical refinement of our understanding of these concepts and their empirical investigation.

Comparisons with findings of other reviews

At the time of writing, we are not aware of a similar review. One closest to our aims is Greenwood & Smith's systematic review of 26 qualitative studies which focus on informal caregiver motivations within the dementia population (Greenwood & Smith, 2019). The themes emerging from our

meta-synthesis can be seen in the narrative synthesis of their review, however, we did not limit our systematic review to dementia caregiving, had a wider search strategy and applied a different type of synthesis. Particular themes align with some of their narrative findings pertaining to obligation to provide care, long-standing familial relationships, affections such as love and a desire to reciprocate or return care (Greenwood & Smith, 2019). By demonstrating their presence across a range of conditions in the current meta-synthesis, we highlight further their importance. Both systematic reviews identify multiple and fluctuating motivations underlying informal care provision. However, our systematic review reveals fewer similarities in caregivers' motivations for caring in relation to the type of relationship with the care recipient, country of origin, ethnic or cultural factors and gender. Greenwood and Smith (2019, p. 15) stated that the 'emphasis on cultural differences may be misleading', whereas we would suggest that understanding of the typically complex content of cultural values, norms and beliefs, their effects on motivations to provide care and acknowledgment of the uniqueness within and between cultures is essential if we are to realise effective multicultural support planning and service provision. The presence of different cultural and social determinants, and the processes and mechanisms that motivate and maintain informal caregiving within distinct cultures, were evident in our findings, for example, with regards to gendered expectations. It was noticeable that cultural values around caregiving were more established for people of Asian ethnic and cultural background than those of Caucasian ethnicity and that these values played a more limited role in motivating care within the latter group (Chao & Roth, 2000; Donovan & Williams, 2015; Globerman, 1996; Han et al., 2008; Hinton et al., 2008; Ho et al., 2003; Holroyd, 2005; Hsueh et al., 2008; Jones et al., 2002; Kao & Stuifbergen, 1999; Kim & Theis, 2000; Kong et al., 2010; Lee et al., 2019; Meyer et al., 2015; Mok et al., 2003; Ng et al., 2016; Park, 2012; Qadir et al., 2013; Qiu et al., 2018; Sasat, 1998; Sheu, 1997; Spitzer et al., 2003; Yamamoto & Wallhagen, 1997; Yeo et al., 2002; Zhang & Lee, 2019). There is a difference between how caregivers from Japan perceive and function in a role of a caregiver due to the cultural norm of primogeniture (Wallhagen & Yamamoto-Mitani, 2006; Yamamoto & Wallhagen, 1997) and how Mexican women assuming the value of '*marianismo*' (pertaining to the 'self-sacrificing mother' in relation to Mother Mary in Christianity) approach the same role. The examples could be multiplied – to mention a few such as the Thai concept of 'Kathany ukatawethi' (Sasat, 1998), Japanese '*Mirutachiba*' (Wallhagen & Yamamoto-Mitani, 2006) or other essential cultural values present in philosophical and religious systems (Anngela-Cole & Busch, 2011; Arpanantikul, 2018; Chao & Roth, 2000; Erickson, 2002; Han et al., 2008; Harris & Long, 1999; Hinton et al., 2008; Kao & Stuifbergen, 1999; Kietzman et al., 2013; Kong et al., 2010; Meyer et al., 2015; Ng et al., 2016; Park, 2012; Park, 2015; Qiu et al., 2018; Sasat, 1998; Spitzer et al., 2003; Strumpf et al., 2001; Sung, 1994; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019) that shape motivations to provide care. It is important, therefore, not to lose sight of the unique and diverse influences on caregiver motivations including those at a more 'macro' level than often considered.

Implications of findings for theory

There are numerous theoretical frameworks for caregiver motivations drawing from various theories (Barber, 2010; Bateson, 1991; Blieszner & Shifflet, 1989; Frank, 2002; Greenberg, 1990; Homans, 1961; Humphrey, 1997; Ryan & Deci, 2000). This meta-synthesis of qualitative studies complements some of the aspects existing in theoretical literature whilst it does not address some other considerations. This review *does not* provide data pertaining to biological or sociobiological motivations to provide care as discussed mainly in the *Reciprocal Altruism Model* and *Kin Selection Model* (Barber, 2010; Humphrey, 1997) and to a lesser extent in the *Empathy Induced Altruism Hypothesis* and *Self-Interest Model* (Bateson, 1991; Greenberg, 1990; Lind & Tyler, 1988). As an example, studies conducted in Africa (Gurayah, 2015; Knight et al., 2016; Kodwo-Nyameazea & Nguyen, 2008; Mahilall, 2006; Muoghalu & Jegede, 2010; Van Sjaak Geest, 2002) included in this review showed that non-relatives were

often involved in providing informal care as opposed to the idea of the survival of the familial gene pool (Schulz et al., 1989). It is not surprising as helping behaviour is thought to be developed not exclusively through (biological) instincts, but also through human experiences and learning where psychological, social and cultural factors play a vital role (Sheu, 1997). Schulz et al. (1989) proposed three perspectives on caregiving motivations pertaining to: social biology, social norms, and psychological motives. The current systematic review contributes to the latter two by considering psychological, social and ethnocultural motivations in caregiving. It extends the latter two perspectives offered by Schulz by (a) developing understanding of macro cultural norms and how a person responds to perceived pressure/expectations of them, and (b) indicating psychological motives, unique reasons for caregiving that have been partially existent in the theoretical considerations – with the commonly mentioned expectations of repayment, receiving esteem or gaining social approval, complying with social norms, seeing oneself as a good person, or avoiding guilt and feeling obliged to provide care. The themes pertaining to cultural and societal determinants of motivations to provide care align also with the *Normative Approach* (Homans, 1961) which describes how caregiver motivations are guided by societal norms (Blieszner & Shifflet, 1989; Johnson et al., 1999). The motives highlighted in our systematic review findings appear not to conform to the basic dichotomy of intrinsic and extrinsic motivations which arose from the *Self-determination Theory* (Ryan & Deci, 2000) and thus we would advise against a generalised and simplified approach to studying motivations to provide informal care. Moreover, findings presented in this systematic review highlight the significance of ‘macro’ processes within the framework of caregiving motivations and willingness to provide care. It is consistent with a general integrative framework of informal caregiving in the illness context (Revenson et al., 2016) which proposes to examine the ‘caregiving process’ in a flexible manner: a general structure that can inform more specific theories. The current systematic review yields such a founding framework that categorises potential ‘macro’ and ‘micro’ predictors of motivations and willingness to provide care, with ‘macro’ level pertaining to culture – and society-dependent factors, which often provide context to ‘micro’ psychological factors (e.g., perceived obligation to provide care). The multidimensional nature of determinants of caregiving motivations is emphasised, i.e., there are multiple factors influencing caregiving motivations and willingness at play.

Implications for policy

Identification and recognition of caregivers’ contribution within society should be a policy priority in countries where it is not applied. The reviewed evidence highlighted that the way policy and service provision are perceived can shape motivations and willingness to provide care (e.g., policy intent, perceived limitations to formal support provision, desire to avoid care home placement). Firstly, a policy underpinning support for caregivers should include the perception of care as primarily a public (governmental) responsibility rather than exclusively filial as demonstrated by caregivers in relation to: the sense of burden when discussing limitations to formal support provision and expectation of a family-based care provision; pressure put on relatives from formal support providers and services; identified policy assumptions that leave no or little place for those who do not want to provide unpaid informal care, yet are expected to do that. Secondly, any policy underpinning support to caregivers should also contain: provision of breaks from caregiving (following expressed need for breaks from caregiving and experiences using respite care services); consideration of the financial costs borne by caregivers and their care recipients ‘*I couldn’t survive without a compensation*’ (Kietzman et al., 2013, p. 532); and regular assessment of caregiver experience, arising needs, and support planning. Given the above, our meta-synthesis emphasises the importance of support for caregivers to sustain their motivations for caring – this is consistent with a report investigating national policies for adult caregivers across Europe published by the European Commission (Bouget et al., 2016).

Implications for health and social care practice

Two key areas which bear relevance to health and social care professionals are *awareness of the caring role* and *recognition of personal values*.

In relation to *the awareness of the role*, it is important to highlight that assumptions that care is given 'out of love' and as an unquestioned part of existing relationships, norms and values can result in caregivers and those around them, not recognising the role they carry out and not identifying with the caregiver role. Meta-synthesis findings demonstrate that real or perceived pressure from other people (including family and care professionals) left little choice when undertaking the caregiving role, and that deviation from societal expectations was expected to elicit negative consequences (Anngela-Cole & Busch, 2011; Arpanantikul, 2018; Bäckström & Sundin, 2010; Han et al., 2008; Holroyd, 2005; Hsu & Shyu, 2003; Kao & Stuijbergen, 1999; Knight et al., 2016; Kong et al., 2010; Kristanti et al., 2019; Leichtentritt et al., 2004; Muoghalu & Jegede, 2010; Qadir et al., 2013; Van Sjaak Geest, 2002; van Wezel et al., 2016; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019). As shown, caregiving is often shaped during socialisation and thus the role may be assumed 'naturally' without conscious thought (Qiu et al., 2018). Helping those providing such care to develop a sense of critical awareness about their caregiving situation and to recognise and report their need for support in their role may be a vital first step that benefits both the caregiver and the care recipient. It requires acknowledging that the nature and provision of support vary both on individual (e.g., the family's emotional support) and public levels (across countries whereas in some of them caregivers are not offered any governmental support at all).

Secondly, there is a need for health and social care professionals to recognise the *personal values* held by caregivers of differing sociocultural backgrounds and how these may affect caregiving motivations/experience. Personal values embrace both individual and supra-individual (i.e., cultural and societal) value types (Rokeach, 2008) with cultural and societal factors strongly manifested in caregiver accounts on both supra-individual and individual levels. Practitioners and service providers may better tailor their support if they acknowledge and act upon caregivers' individual and supra-individual values and needs. The dominant sociocultural narrative appears to expect that care provision remains predominantly within the family with the core belief expressed in the current systematic review findings indicating that being cared for at home is preferable to care home placement as it is more individualised (Cash et al., 2013; Dumit et al., 2015; Han et al., 2008; Hsueh et al., 2008; Leichtentritt et al., 2004; Nkongho & Archbold, 1995; Parveen et al., 2011; Spitzer et al., 2003; van Wezel et al., 2016). Cultural values added a further dimension to motivations to provide care (Donovan & Williams, 2015; Han et al., 2008; Hinton et al., 2008; Ho et al., 2003; Hsueh et al., 2008; Jones et al., 2002; Jones et al., 2003; Kong et al., 2010; Leichtentritt et al., 2004; Mendez-Luck & Anthony, 2016; Meyer et al., 2015; Mok et al., 2003; Ng et al., 2016; Park, 2015; Qadir et al., 2013; Sasat, 1998; Sheu, 1997; van Wezel et al., 2016; Yeo et al., 2002; Zhang & Lee, 2019) highlighting a need for culturally-sensitive caregiver assessment and support planning processes.

Both the above domains arising from this systematic review findings align with the recommendations for *caregiver assessment* presented by Seddon and Robinson (2015) in the British context. Caregiver assessment should leave space for 1:1 discussion of the rarely acknowledged motives that drive and maintain caregivers in their roles (Cash et al., 2013; Park, 2015), roles which should not be taken for granted. A dialogue with carers (conversational assessment), separate from a caregiver assessment, is required to enable the provision of person-centred, outcome-focused support for caregivers that is sensitive to their motivations for caring and their unique circumstances (Skills for Care, 2018).

Implications for research

This large and inclusive systematic review highlights the need for prospective longitudinal qualitative studies to better understand shifting patterns of motivations to care, willingness to care and the

influences thereon. Furthermore, research conducted outside the Caucasian context and the western developed world is lacking, and there is an underrepresentation of male caregivers in studies – although this may improve over time as the gender balance within caregiving levels (Kramer & Thompson, 2002). Whilst there are some areas where we lack confidence in the generalisability of findings, there is sufficient evidence to begin to pilot and evaluate tailored interventions that address the individualised needs of caregivers and which take into consideration motivations and willingness within sociocultural and often dynamic contexts. For example, interventions targeting caregivers' beliefs and expectancies, coping skills or social resourcefulness may help maintain motivations and willingness to provide care, i.e., caregiving motivations and willingness can be addressed indirectly by targeting specific aspects of the caring experience.

Future research should strive to differentiate between primary and secondary caregiving motivations considering that these may shift given the temporal context of many illnesses. This points to the significant issue of publication bias in the field of informal caregiving, where the voice of those who relinquish the caring role is limited. As an example from this meta-synthesis, it needs further investigation whether stigma and the expectation of stigma could actually prevent caregiving as data from people who chose not to provide care was not obtained in this meta-synthesis (Lauritzen et al., 2019; Leichtenritt et al., 2004; Park, 2012). Finally, this systematic review considers only current caregivers and is unable to identify and describe influences on the choices of those who have chosen not to provide care. Given demographic changes and future care needs it will be important for research to explore people's anticipatory willingness to take on the caregiving role.

Strengths and limitations

A strength of this systematic review is its comprehensive nature: international evidence is reviewed using studies from across the globe; 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 inductive identification of 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 selected subpopulations of caregivers.

The data presented within the reviewed studies did not enable identification of what, if any, motivations to provide care were considered by caregivers to be primary in terms of societal and cultural influences. It should not, therefore, be assumed that the most frequently mentioned motivations were the most salient for caregivers, especially given the complex and multiple motivations identified. Social desirability may have also influenced what and how motivations and willingness were reported, and furthermore, motivations may be latent/not always conscious (Greenwood et al., 2018; Greenwood & Smith, 2019).

Notes

1. See (Arpanantikul, 2018; Chao & Roth, 2000; Harris & Long, 1999; Holroyd, 2001, 2003, 2005; Hsu & Shyu, 2003; Kao & Stuifbergen, 1999; Kristanti et al., 2019; Kuşçu et al., 2009; Lee et al., 2019; Leichtenritt 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).
2. See (Gurayah, 2015; Knight et al., 2016; Kodwo-Nyameazee & Nguyen, 2008; Mahilall, 2006; Muoghalu & Jegede, 2010; Van Sjaak Geest, 2002).
3. See (Albinsson & Strang, 2003; Bäckström & Sundin, 2010; Bashir, 2014; 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,

- Vatne, and Rokstad, 2017; Tretteteig, Vatne, Rokstad et al., 2017; Vellone et al., 2002; Wallroth, 2016; Williams et al., 2014).
4. See (Albinsson & Strang, 2003; Alonso et al., 2018; Anngela-Cole & Busch, 2011; Aronson, 1992; Browne Sehy, 1998; Cahill, 1999; Clark & Huttlinger, 1998; de Leon Arabit, 2005; Donovan & Williams, 2015; Donorfio & Kellett, 2006; Dunér, 2010; Erickson, 2002; Funk, 2012; Gerdner et al., 2007; Globerman, 1996; Guberman et al., 1992; Han et al., 2008; Hanyok et al., 2009; Harris, 1998; Hinton et al., 2008; Ho et al., 2003; Hsueh et al., 2008; Jones et al., 2002, 2003; Kietzman et al., 2013; Kim, 2009; Kim & Theis, 2000; Kong et al., 2010; Lewis et al., 1995; Mars, 2015; McDermott & Mendez-Luck, 2018; Mendez-Luck & Anthony, 2016; Merrill, 1996; Meyer et al., 2015; Morgan & Laing, 1991; Murphy, 2005; Neufeld & Harrison, 1998; Nkongho & Archbold, 1995; Opie, 1994; Park, 2012; Pelusi, 1999; Pierce, 2001; Russell, 2001; Sheu, 1997; Spitzer et al., 2003; Stajduhar et al., 2008; Sterritt & Pokorny, 1998; Strumpf et al., 2001; Sung, 1994; Wallhagen & Yamamoto-Mitani, 2006; Weinland, 2009; Wiles, 2002; Yeo et al., 2002).
 5. See (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, 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).
 6. See (Chao & Roth, 2000; Kim & Theis, 2000; Leichtentritt et al., 2004; Muoghalu & Jegede, 2010; Weinland, 2009).
 7. See (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).
 8. See (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, Vatne, & Rokstad, 2017; Tretteteig, Vatne, Rokstad et al., 2017; Vellone et al., 2002; Wallroth, 2016; Williams et al., 2014).
 9. See (Alonso et al., 2018; Arpanantikul, 2018; Bäckström & Sundin, 2010; Bashir, 2014; Bryant & Lim, 2013; Chao & Roth, 2000; Donorfio & Kellett, 2006; Donovan & Williams, 2015; Dumit et al., 2015; Dunér, 2010; Foster, 2012; Funk, 2012; Guberman et al., 1992; Han et al., 2008; Hinton et al., 2008; Ho et al., 2003; Holroyd, 2001; Holroyd, 2003; Holroyd, 2005; Hsu & Shyu, 2003; Hsueh et al., 2008; Jones et al., 2002; Jones et al., 2003; Kao & Stuijbergen, 1999; Kim, 2009; Kim & Theis, 2000; Kong et al., 2010; Kristanti et al., 2019; Lauritzen et al., 2019; Lee et al., 2019; Li et al., 2012; McDonnell & Ryan, 2014; Merrill, 1996; Meyer et al., 2015; Mok et al., 2003; Ng et al., 2016; Öhman & Söderberg, 2004; Pang & Lee, 2019; Park, 2012; Qadir et al., 2013; Qiu et al., 2018; Quinn, 2009; Russell, 2001; Sheu, 1997; Sand et al., 2010; Sasat, 1998; Spitzer et al., 2003; Tretteteig, Vatne, & Rokstad, 2017; Tretteteig, Vatne, Rokstad et al., 2017; Wallroth, 2016; Williams et al., 2014; Yamamoto & Wallhagen, 1997; Yeo et al., 2002; Zhang & Lee, 2019).
 10. See (Clark & Huttlinger, 1998; de Leon Arabit, 2005; Gerdner et al., 2007; Mars, 2015; McDermott & Mendez-Luck, 2018; Mendez-Luck & Anthony, 2016; Nkongho & Archbold, 1995; Pierce, 2001; Sterritt & Pokorny, 1998; Weinland, 2009).
 11. See (Gurayah, 2015; Knight et al., 2016; Kodwo-Nyameazea & Nguyen, 2008; Mahilall, 2006; Muoghalu & Jegede, 2010; Van Sjaak Geest, 2002); Arab ethnicity ($N = 2$) (Kuşçu et al., 2009; Leichtentritt et al., 2004).
 12. See (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).
 13. See (Anngela-Cole & Busch, 2011; Knight & Sayegh, 2010; Muoghalu & Jegede, 2010; Rivera et al., 2009; Strumpf et al., 2001; Van Sjaak Geest, 2002).
 14. See (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, 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).
 15. See (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).
 16. See (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, 2008; Lewis et al., 1995; Merrill, 1996; Statham, 2003; Sung, 1994; Van Sjaak Geest, 2002; Wallroth, 2016; Weinland, 2009).
 17. See (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; Leichtentritt 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, Vatne, & Rokstad, 2017; Tretteteig, Vatne, Rokstad et al., 2017; van Wezel et al., 2016; Vellone et al., 2002; Wallhagen & Yamamoto-Mitani, 2006; Yamamoto & Wallhagen, 1997; Yeo et al., 2002).
18. See (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).
 19. See (Bäckström & Sundin, 2010; de Leon Arabit, 2005; Pierce, 2001; Qiu et al., 2018; Zhang & Lee, 2019).
 20. See (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).
 21. See (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).
 22. See (Almeida et al., 2018; Alonso et al., 2018; Albinsson & Strang, 2003; Arpanantikul, 2018; Bäckström & Sundin, 2010; Boeije et al., 2003; Browne Sehy, 1998; Bryant & Lim, 2013; Chao & Roth, 2000; Clark & Huttlinger, 1998; de Leon Arabit, 2005; Donovan & Williams, 2015; Donorfio & Kellett, 2006; Dumit et al., 2015; Foster, 2012; Gerdner et al., 2007; Globerman, 1996; Han et al., 2008; Harris, 1998; Ho et al., 2003; Holroyd, 2005; Hsu & Shyu, 2003; Hsueh et al., 2008; Jones et al., 2002, 2003; Kietzman et al., 2013; Kim, 2009; Kodwo-Nyameazea & Nguyen, 2008; Kristanti et al., 2019; Kong et al., 2010; Lauritzen et al., 2019; Lee et al., 2019; Leichtentritt et al., 2004; Li et al., 2012; Lin et al., 2012; Mahilall, 2006; McDermott & Mendez-Luck, 2018; McDonnell & Ryan, 2014; Meyer et al., 2015; Mok et al., 2003; Murphy, 2005; Neufeld & Harrison, 1998; Ng et al., 2016; Öhman & Söderberg, 2004; Pang & Lee, 2019; Parveen et al., 2011; Pierce, 2001; Qiu et al., 2018; Sand et al., 2010; Sheu, 1997; Statham, 2003; Tretteteig, Vatne, & Rokstad, 2017; Tretteteig, Vatne, Rokstad et al., 2017; Wallroth, 2016; Weinland, 2009; Williams et al., 2014; Zhang & Lee, 2019).
 23. See (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, 2005; 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).
 24. See (Asahara et al., 2002; Kellett, 1999; McDonnell et al., 1991; Piotrowska, 2015; Takigiku et al., 1993).
 25. See (Browne Sehy, 1998; Chao & Roth, 2000; Globerman, 1996; Harris & Long, 1999; Holroyd, 2005; Hsueh et al., 2008; Kao & Stuijbergen, 1999; Kietzman et al., 2013; Kim & Theis, 2000; Lee et al., 2019; Leichtentritt et al., 2004; Muoghalu & Jegede, 2010; Ng et al., 2016; Park, 2012; Park, 2015; Parveen et al., 2011; Qiu et al., 2018; Sasat, 1998; Sheu, 1997; Spitzer et al., 2003; Van Sjaak Geest, 2002; van Wezel et al., 2016; Wallhagen & Yamamoto-Mitani, 2006; Yamamoto & Wallhagen, 1997).
 26. See (Anngela-Cole & Busch, 2011; Chao & Roth, 2000; Han et al., 2008; Harris & Long, 1999; Hinton et al., 2008; Kao & Stuijbergen, 1999; Kietzman et al., 2013; Kong et al., 2010; Meyer et al., 2015; Ng et al., 2016; Park, 2012; Park, 2015; Qiu et al., 2018; Spitzer et al., 2003; Sung, 1994; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019).
 27. See (Donovan & Williams, 2015; Harris & Long, 1999; Hinton et al., 2008; Holroyd, 2005; Hsueh et al., 2008; Jones et al., 2002; Mendez-Luck & Anthony, 2016; Mok et al., 2003; Park, 2015; Parveen et al., 2011; Qiu et al., 2018; Sheu, 1997; Spitzer et al., 2003; van Wezel et al., 2016; Zhang & Lee, 2019).
 28. See (Donovan & Williams, 2015; Han et al., 2008; Hinton et al., 2008; Ho et al., 2003; Hsueh et al., 2008; Jones et al., 2002; Jones et al., 2003; Kong et al., 2010; Leichtentritt et al., 2004; Mendez-Luck & Anthony, 2016; Meyer et al., 2015; Mok et al., 2003; Ng et al., 2016; Park, 2015; Qadir et al., 2013; Sasat, 1998; Sheu, 1997; van Wezel et al., 2016; Yeo et al., 2002; Zhang & Lee, 2019).
 29. See (Anngela-Cole & Busch, 2011; Arpanantikul, 2018; Chao & Roth, 2000; Erickson, 2002; Han et al., 2008; Harris & Long, 1999; Hinton et al., 2008; Kao & Stuijbergen, 1999; Kietzman et al., 2013; Kong et al., 2010; Mendez-Luck & Anthony, 2016; Meyer et al., 2015; Mok et al., 2003; Ng et al., 2016; Park, 2012; Park, 2015; Qiu et al., 2018; Sasat, 1998; Spitzer et al., 2003; Strumpf et al., 2001; Sung, 1994; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019).
 30. See (Anngela-Cole & Busch, 2011; Browne Sehy, 1998; Chao & Roth, 2000; Globerman, 1996; Guberman et al., 1992; Hinton et al., 2008; Ho et al., 2003; Holroyd, 2001; Jones et al., 2002; Kodwo-Nyameazea & Nguyen, 2008; McDermott & Mendez-Luck, 2018; Nkongho & Archbold, 1995; Park, 2015; Qiu et al., 2018; Sheu, 1997; Spitzer et al., 2003; Wallhagen & Yamamoto-Mitani, 2006; Yamamoto & Wallhagen, 1997).
 31. See (Bashir, 2014; Harris, 1998; Hinton et al., 2008; McDermott & Mendez-Luck, 2018; Mendez-Luck & Anthony, 2016; Park, 2015; Sheu, 1997; Wallhagen & Yamamoto-Mitani, 2006).
 32. See (Anngela-Cole & Busch, 2011; Arpanantikul, 2018; Erickson, 2002; Harris, 1998; Hinton et al., 2008; Kristanti et al., 2019; Leichtentritt et al., 2004; Mahilall, 2006; Muoghalu & Jegede, 2010; Ng et al., 2016; Qadir et al., 2013; Strumpf et al., 2001; Sung, 1994; van Wezel et al., 2016; Vellone et al., 2002).
 33. See (Alonso et al., 2018; Arpanantikul, 2018; Guberman et al., 1992; Hinton et al., 2008; Kao & Stuijbergen, 1999; Kim, 2009; Kong et al., 2010; Mahilall, 2006; Muoghalu & Jegede, 2010; Park, 2012; Park, 2015; Qadir et al., 2013;

- Sasat, 1998; Strumpf et al., 2001; Sung, 1994; van Wezel et al., 2016; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019).
34. See (Bryant & Lim, 2013; Donovan & Williams, 2015; Han et al., 2008; Hsueh et al., 2008; Jones et al., 2002; Kim, 2009; Kodwo-Nyameazea & Nguyen, 2008; Kong et al., 2010).
 35. See (Anngela-Cole & Busch, 2011; Arpanantikul, 2018; Bäckström & Sundin, 2010; Han et al., 2008; Holroyd, 2005; Hsu & Shyu, 2003; Kao & Stuijbergen, 1999; Knight et al., 2016; Kong et al., 2010; Kristanti et al., 2019; Leichtentritt et al., 2004; Muoghalu & Jegede, 2010; Qadir et al., 2013; Van Sjaak Geest, 2002; van Wezel et al., 2016; Yamamoto & Wallhagen, 1997; Zhang & Lee, 2019).
 36. See (Almeida et al., 2018; Aronson, 1992; Arpanantikul, 2018; Bryant & Lim, 2013; Cahill, 1999; Chao & Roth, 2000; Clark & Huttlinger, 1998; Donorfio & Kellett, 2006; Donovan & Williams, 2015; Globberman, 1996; Holroyd, 2001; Holroyd, 2005; Kietzman et al., 2013; Knight et al., 2016; Kodwo-Nyameazea & Nguyen, 2008; McDermott & Mendez-Luck, 2018; McDonnell & Ryan, 2014; Merrill, 1996; Muoghalu & Jegede, 2010; Ng et al., 2016; Qadir et al., 2013; Rivera et al., 2009; Spitzer et al., 2003; Sterritt & Pokorny, 1998; van Wezel et al., 2016; Wallroth, 2016; Wiles, 2002; Yamamoto & Wallhagen, 1997; Yeo et al., 2002).
 37. See (Almeida et al., 2018; Donovan & Williams, 2015; Guberman et al., 1992; Hsueh et al., 2008; Kim, 2009; Kodwo-Nyameazea & Nguyen, 2008; Kristanti et al., 2019; Leichtentritt et al., 2004; Lewis et al., 1995; Øydgard, 2017; Parveen et al., 2011; Qiu et al., 2018; Vellone et al., 2002).
 38. See (Boeije et al., 2003; Bryant & Lim, 2013; de Leon Arabit, 2005; Guberman et al., 1992; Han et al., 2008; Ho et al., 2003; Hsueh et al., 2008; Jones et al., 2002; Kong et al., 2010; Lewis et al., 1995; McDonnell & Ryan, 2014; Murphy, 2005; Nkongho & Archbold, 1995; Qiu et al., 2018; Rivera et al., 2009; Russell, 2001; Sasat, 1998; Statham, 2003; van Wezel et al., 2016; Wiles, 2002; Yeo et al., 2002).
 39. See (Cash et al., 2013; Dumit et al., 2015; Han et al., 2008; Hsueh et al., 2008; Leichtentritt et al., 2004; Nkongho & Archbold, 1995; Parveen et al., 2011; Spitzer et al., 2003; van Wezel et al., 2016).
 40. See (Donovan & Williams, 2015; Guberman et al., 1992; Kietzman et al., 2013; McDonnell & Ryan, 2014; Parveen et al., 2011; Qiu et al., 2018).

Acknowledgements

This systematic review was undertaken as part of postgraduate study conducted by author Mikołaj Zarzycki. 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 together 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.

Disclosure statement

No potential conflict of interest was reported by the author(s).

Funding

The PhD was funded by Horizon 2020 - Marie Skłodowska - Curie actions - Innovative Training Network Grant Agreement number: 814072 — ENTWINE — H2020-MSCA-ITN-2018.

Data availability statement

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

ORCID

Mikołaj Zarzycki  <http://orcid.org/0000-0002-8357-563X>

Val Morrison  <http://orcid.org/0000-0002-4308-8976>

Eva Bei  <http://orcid.org/0000-0002-3093-0829>

Diane Seddon  <http://orcid.org/0000-0002-0660-4839>

References

- Abell, N. (2001). Assessing willingness to care for persons with AIDS: Validation of a new measure. *Research on Social Work Practice, 11*(1), 118–130. <https://doi.org/10.1177/104973150101100108>
- Albertini, M., Kohli, M., & Vogel, C. (2007). Intergenerational transfers of time and money in European families: Common patterns—different regimes? *Journal of European Social Policy, 17*(4), 319–334. <https://doi.org/10.1177/0958928707081068>
- Albinsson, L., & Strang, P. (2003). Existential concerns of families of late-stage. *Journal of Palliative Medicine, 6*(2), 225–235. <https://doi.org/10.1089/109662103764978470>
- Al-Janabi, H., Carmichael, F., Oyeboode, J., Al-Janabi, H., Carmichael, F., & Oyeboode, J. (2018). Informal care: Choice or constraint? *Scandinavian Journal of Caring Sciences, 32*(1), 157–167. <https://doi.org/10.1111/scs.12441>
- Almeida, L. P. B., Menezes, T. M. O., Freitas, A. V. S., & Pedreira, L. C. (2018). Social and demographic characteristics of elderly caregivers and reasons to care for elderly people at home. *REME: Revista Mineira de Enfermagem, 22*, e-1074. <https://doi.org/10.5935/1415-2762.20180004>
- Alonso, W. W., Kitko, L. A., & Hupcey, J. E. (2018). Intergenerational caregivers of parents with end-stage heart failure. *Research and Theory for Nursing Practice, 32*(4), 413–435. <https://doi.org/10.1891/1541-6577.32.4.413>
- Anngela-Cole, L., & Busch, M. (2011). Stress and grief among family caregivers of older adults with cancer: A multicultural comparison from Hawai'i. *Journal of Social Work in End-Of-Life & Palliative Care, 7*(4), 318–337. <https://doi.org/10.1080/15524256.2011.623460>
- Aronson, J. (1992). Women's sense of responsibility for the care of old people: "But who else is going to do it?" *Gender & Society, 6*(1), 8–29. <https://doi.org/10.1177/089124392006001002>
- Arpanantikul, M. (2018). Women's perspectives on home-based care for family members with chronic illness: An interpretive phenomenology study. *Nursing & Health Sciences, 20*(4), 494–501. <https://doi.org/10.1111/nhs.12541>
- Asahara, K., Momose, Y., & Murashima, S. (2002). Family caregiving of the elderly and long-term care insurance in rural Japan. *International Journal of Nursing Practice, 8*(3), 167–172. <https://doi.org/10.1046/j.1440-172X.2002.00358.x>
- Baca Zinn, M., & Wells, B. (2000). Diversity within Latino families: New lessons for family social science. In D. Demo, K. Allen, & M. A. Fine (Eds.), *Handbook of family diversity* (pp. 252–273). Oxford University Press.
- Bäckström, B., & Sundin, K. (2010). The experience of being a middle-aged close relative of a person who has suffered a stroke – Six months after discharge from a rehabilitation clinic. *Scandinavian Journal of Caring Sciences, 24*(1), 116–124. <https://doi.org/10.1111/j.1471-6712.2009.00694.x>
- Baker, G. P., Jensen, M. C., & Murphy, K. J. (1988). Compensation and incentives: Practice vs. theory. *The Journal of Finance, 43*(3), 593–616. <https://doi.org/10.1111/j.1540-6261.1988.tb04593.x>
- Bambra, C. (2005). Worlds of welfare and the health care discrepancy. *Social Policy and Society, 4*(1), 31–41. <https://doi.org/10.1017/S1474746404002143>
- Barber, N. (2010). *Kindness in a cruel world: The evolution of altruism*. Prometheus Books.
- Bashir, N. (2014). The drivers and impacts of family obligations and overseas remittances practices: A case study of Pakistani-origin individuals in the UK. *Social Policy and Society, 13*(2), 177–188. <https://doi.org/10.1017/S1474746413000493>
- Bateson, C. D. (1991). *The Altruism question: Toward a social-psychological answer*. Psychology Press.
- Bauer, J. M., & Sousa-Poza, A. (2015). Impacts of informal caregiving on caregiver employment, health, and family. *Journal of Population Ageing, 8*(3), 113–145. <https://doi.org/10.1007/s12062-015-9116-0>
- Bettio, F., & Verashchagina, A. (2010). *Long-term care for the elderly: Provisions and providers in 33 European countries*. Publications Office of the EU.
- Blieszner, R., & Shifflet, P. A. (1989). Affection, communication, and commitment in adult-child caregiving for parents with Alzheimer's disease. In J. A. Mancini (Ed.), *Aging parents and adult children* (pp. 231–242). Lexington Books.
- Boeije, H. R., Duijnste, M. S. H., & Grypdonck, M. H. F. (2003). Continuation of caregiving among partners who give total care to spouses with multiple sclerosis. *Health & Social Care in the Community, 11*(3), 242–252. <https://doi.org/10.1046/j.1365-2524.2003.00422.x>
- Booth, A. (2016). Searching for qualitative research for inclusion in systematic reviews: A structured methodological review. *Systematic Reviews, 5*(74), 1–23. <https://doi.org/10.1186/s13643-016-0249-x>
- Börsch-Supan, A. (2019). *Survey of health, ageing and retirement in Europe (SHARE) Wave 7*. Release version: 700 SHARE-ERIC. <https://doi.org/oi:10.6103/SHARE.w7.700>
- Bouquet, D., Spasova, S., & Vanhercke, B. (2016). *Work-life balance measures for persons of working age with dependent relatives in Europe. A study of national policies*. Eur Soc Prot Netw. Brussels: European Commission. Available: <https://www.researchgate.net/publication/305115112>
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>
- Bridges, B. J. (1995). *Therapeutic caregiving: A practical guide for caregivers of persons with Alzheimer's and other dementia causing diseases*. Bjb Pub.
- Browne Sehy, Y. A. (1998). Moral decision-making by elderly women caregivers: A feminist perspective on justice and care. <https://doi.org/10.1017/CBO9781107415324.004>

- Bryant, L., & Lim, S. (2013). Australian-Chinese families caring for elderly relatives. *Ageing and Society*, 33(8), 1401–1421. <https://doi.org/10.1017/S0144686X12000657>
- Burridge, L., Winch, S., & Clavarino, A. (2007). Reluctance to care. *Cancer Nursing*, 30(2), E9–E19. <https://doi.org/10.1097/01.ncc.0000265298.17394.e0>
- Cahill, S. M. (1999). Caring in families: What motivates wives, daughters, and daughters-in-law to provide dementia care? *Journal of Family Studies*, 5(2), 235–247. <https://doi.org/10.5172/jfs.5.2.235>
- Camden, A., Livingston, G., & Cooper, C. (2011). Reasons why family members become carers and the outcome for the person with dementia: Results from the CARD study. *International Psychogeriatrics*, 23(9), 1442–1450. <https://doi.org/10.1017/S1041610211001189>
- Carers UK. (2019a). *State of caring. A snapshot of unpaid care in the UK*. Carers UK.
- Carers UK. (2019b). *Facts about carers 2019*. Policy Brief. 000: 1–11. https://www.carersuk.org/images/Facts_about_Carers_2019.pdf.
- Cash, B., Hodgkin, S., & Warburton, J. (2013). Till death us do part? A critical analysis of obligation and choice for spousal caregivers. *Journal of Gerontological Social Work*, 56(8), 657–674. <https://doi.org/10.1080/01634372.2013.823472>
- CASP. (2014). *Critical appraisal skills programme (CASP) qualitative checklist*. <https://casp-uk.net/casp-tools-checklists/>
- Cerasoli, C. P., Nicklin, J. M., & Ford, M. T. (2014). Intrinsic motivation and extrinsic incentives jointly predict performance: A 40-year meta-analysis. *Psychological Bulletin*, 140(4), 980–1008. <https://doi.org/10.1037/a0035661>
- Chalmers, B. (1996). Western and African conceptualizations of health. *Psychology & Health*, 12(1), 1–10. <https://doi.org/10.1080/08870449608406915>
- Chamberlain, C., Ralph, N., Hokke, S., Clark, Y., Gee, G., & Stansfield, C. (2019). Healing the past by nurturing the future: A qualitative systematic review and metasynthesis of pregnancy, birth and early postpartum experiences and views of parents with a history of childhood maltreatment. *PLoS One*, 14(12), e0225441. <https://doi.org/10.1371/journal.pone.0225441>
- Chao, S. Y., & Roth, P. (2000). The experiences of Taiwanese women caring for parents-in-law. *Journal of Advanced Nursing*, 31(3), 631–638. <https://doi.org/10.1046/j.1365-2648.2000.01319.x>
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. Sage.
- Clark, M., & Huttlinger, K. (1998). Elder care among Mexican American families. *Clinical Nursing Research*, 7(1), 64–81. <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=107251285&site=ehost-live>. <https://doi.org/10.1177/105477389800700106>
- de Leon Arabit, L. (2005). Coping strategies of Latino women caring for a spouse recovering from a stroke: A grounded theory. *Journal of Theory Construction & Testing*, 12(2), 42–49. <http://ezproxy.bangor.ac.uk/login?url=https://www.proquest.com/scholarly-journals/coping-strategies-latino-women-caring-spouse/docview/219214366/se-2?accountid=14874>
- Del-Pino-Casado, R., Frías-Osuna, A., & Palomino-Moral, P. A. (2011). Subjective burden and cultural motives for caregiving in informal caregivers of older people. *Journal of Nursing Scholarship*, 43(3), 282–291. <https://doi.org/10.1111/j.1547-5069.2011.01407.x>
- Dilworth-Anderson, P., Brummett, B. H., Goodwin, P., Williams, S. W., Williams, R. B., & Siegler, I. C. (2005). Effect of race on cultural justifications for caregiving. *Journals Gerontol Ser B Psychol Sci Soc Sci*, 60B(5), 257. <https://doi.org/10.1093/geronb/60.5.S257>
- Donorfio, L. K. M., & Kellett, K. (2006). Filial responsibility and transitions involved: A qualitative exploration of caregiving daughters and frail mothers. *Journal of Adult Development*, 13(3-4), 158–167. <https://doi.org/10.1007/s10804-007-9025-4>
- Donovan, R., & Williams, A. M. (2015). Care-giving as a Canadian-Vietnamese tradition: “It’s like eating, you just do it”. *Health & Social Care in the Community*, 23(1), 79–87. <https://doi.org/10.1111/hsc.12126>
- Dumit, N. Y., Abboud, S., Massouh, A., & Magilvy, J. K. (2015). Role of the Lebanese family caregivers in cardiac self-care: A collective approach. *Journal of Clinical Nursing*, 24(21–22), 3318–3326. <https://doi.org/10.1111/jocn.12949>
- Dunér, A. (2010). Motives, experiences and strategies of next of kin helping older relatives in the Swedish welfare context: A qualitative study. *International Journal of Social Welfare*, 19(1), 54–62. <https://doi.org/10.1111/j.1468-2397.2008.00631.x>
- Dykstra, P. A., & Fokkema, T. (2012). Norms of filial obligation in the Netherlands. *Population*, 67(1), 97–122. <https://doi.org/10.3917/pope.1201.0097>
- EPPI-Centre. (2010). *EPPI-centre methods for conducting systematic reviews*. The Social Science Research Unit, Institute of Education, University of London.
- EPPI-Centre SSRU, EPPI-Centre. (2002). *Core keywording strategy: Data collection for a register of educational research*. Version 0.9. 7. EPPI-Centre, Social Science Research Unit London.
- Erickson, M. E. (2002). *Effects of motivation, roles, coping strategies, and adaptations in relationships and personality on caretaking of elderly parents by midlife couples*. Walden University.
- Fawcett, B. (2014). Well-being and older people: The place of day clubs in reconceptualising participation and challenging deficit. *British Journal of Social Work*, 44(4), 831–848. <https://doi.org/10.1093/bjsw/bcs145>
- Fisher, W. A., Fisher, J. D., & Harman, J. (2003). The information-motivation-behavioral skills model: A general social psychological approach to understanding and promoting health behavior. In J. Suis, & K. A. Wallston (Eds.), *Social psychological foundations of health and illness* (pp. 82–106). <https://doi.org/10.1002/9780470753552.ch4>

- Foster, L. (2012). *An investigation into the impact of dementia on couples and how they cope with this* [Doctoral dissertation, University of Bath]. <https://doi.org/10.1007/s13398-014-0173-7.2>.
- Franco, L. M., Bennett, S., & Kafner, R. (2002). Health sector reform and public sector health worker motivation: A conceptual framework. *Social Science & Medicine*, 54(8), 1255–1266. <http://www.hrresourcecenter.org/node/1095>. [https://doi.org/10.1016/S0277-9536\(01\)00094-6](https://doi.org/10.1016/S0277-9536(01)00094-6)
- Frank, R. H. (2002). Altruism in competitive environments. In R. J. D. A. Harrington, D. L. X. Bstan, & T. Gyatsho (Eds.), *Visions of compassion: Western scientists and Tibetan Buddhists examine human nature* (pp. 182–210). Oxford University Press.
- Funk, L. M. (2012). “Returning the love”, not “balancing the books”: Talk about delayed reciprocity in supporting ageing parents. *Ageing and Society*, 32(4), 634–654. <https://doi.org/10.1017/S0144686X11000523>
- Geertz, C. (1973). *The interpretation of cultures*. Basic books.
- Gerdner, L. A., Tripp-Reimer, T., & Simpson, H. C. (2007). Hard lives, God’s help, and struggling through: Caregiving in Arkansas delta. *Journal of Cross-Cultural Gerontology*, 22(4), 355–374. <https://doi.org/10.1007/s10823-007-9047-1>
- Globerman, J. (1996). Motivations to care: Daughters-and sons-in-law caring for relatives with Alzheimer’s disease. *Family Relations*, 45(1), 37–45. <https://doi.org/10.2307/584768>
- Gough, D., Oliver, S., & Thomas, J. (2017). *An introduction to systematic reviews*. Sage.
- Greenberg, J. (1990). Organizational justice: Yesterday, today, and tomorrow. *Journal of Management*, 16(2), 399–432. <https://doi.org/10.1177/014920639001600208>
- Greenwood, N., McKeivitt, C., & Milne, A. (2018). Carer research: Time to rebalance? *Journal of the Royal Society of Medicine*, 111(7), 253–254. <https://doi.org/10.1177/0141076818779204>
- Greenwood, N., & Smith, R. (2019). Motivations for being informal carers of people living with dementia: A systematic review of qualitative literature. *BMC Geriatrics*, 19(1). <https://doi.org/10.1186/s12877-019-1185-0>
- Guberman, N., Maheu, P., & Maillé, C. (1992). Women as family caregivers: Why do they care? *The Gerontologist*, 32(5), 607–617. <https://doi.org/10.1093/geront/32.5.607>
- Gurayah, T. (2015). Caregiving for people with dementia in a rural context in South Africa. *South African Family Practice*, 57(3), 194–197. <https://doi.org/10.1080/20786190.2014.976946>
- Han, H. R., Choi, Y. J., Kim, M. T., Lee, J. E., & Kim, K. B. (2008). Experiences and challenges of informal caregiving for Korean immigrants. *Journal of Advanced Nursing*, 63(5), 517–526. <https://doi.org/10.1111/j.1365-2648.2008.04746.x>
- Hanyok, L. A., Mullaney, J., Finucane, T., & Carrese, J. (2009). Potential caregivers for homebound elderly: More numerous than supposed? *The Journal of Family Practice*, 58(7), 1–6.
- Harris, P. B. (1998). Listening to caregiving sons: Misunderstood realities. *The Gerontologist*, 38(3), 342–352. <https://doi.org/10.1093/geront/38.3.342>
- Harris, P. B., & Long, S. O. (1999). Husbands and sons in the United States and Japan: Cultural expectations and caregiving experiences. *Journal of Aging Studies*, 13(3), 241–267. [https://doi.org/10.1016/S0890-4065\(99\)80096-6](https://doi.org/10.1016/S0890-4065(99)80096-6)
- Hidi, S., & Harackiewicz, J. M. (2000). Motivating the academically unmotivated: A critical issue for the 21st century. *Review of Educational Research*, 70(2), 151–179. <https://doi.org/10.3102/00346543070002151>
- Hinton, L., Tran, J. N., Tran, C., & Hinton, D. (2008). Religious and spiritual dimensions of the Vietnamese dementia caregiving experience. *Hallym International Journal of Aging*, 10(2), 139–160. <https://doi.org/10.2190/HA.10.2.e>
- Ho, B., Friedland, J., Rappolt, S., & Noh, S. (2003). Caregiving for relatives with Alzheimer’s disease: Feelings of Chinese-Canadian women. *Journal of Aging Studies*, 17(3), 301–321. [https://doi.org/10.1016/S0890-4065\(03\)00028-8](https://doi.org/10.1016/S0890-4065(03)00028-8)
- Hoffmann, F., & Rodrigues, R. (2010). *Informal carers: Who takes care of them?* Policy Brief. Vienna.
- Holroyd, E. (2001). Hong Kong Chinese daughters’ intergenerational caregiving obligations: A cultural model approach. *Social Science & Medicine*, 53(9), 1125–1134. [https://doi.org/10.1016/S0277-9536\(00\)00406-8](https://doi.org/10.1016/S0277-9536(00)00406-8)
- Holroyd, E. (2005). Developing a cultural model of caregiving obligations for elderly Chinese wives. *Western Journal of Nursing Research*, 27(4), 437–456. <https://doi.org/10.1177/0193945905274907>
- Holroyd, E. E. (2003). Chinese family obligations toward chronically ill elderly members: Comparing caregivers in Beijing and Hong Kong. *Qualitative Health Research*, 13(3), 302–318. <https://doi.org/10.1177/1049732302250127>
- Homans, G. C. (1961). *Social behavior: Its elementary forms*. Harcourt.
- Hsu, H. C., & Shyu, Y. L. I. L. (2003). Implicit exchanges in family caregiving for frail elders in Taiwan. *Qualitative Health Research*, 13(8), 1078–1093. <https://doi.org/10.1177/1049732303256370>
- Hsueh, K. H., Hu, J., & Clarke-Ekong, S. (2008). Acculturation in filial practices among US Chinese caregivers. *Qualitative Health Research*, 18(6), 775–785. <https://doi.org/10.1177/1049732308318923>
- Hughes, M., & Heycox, K. (2020). *Older people, ageing and social work: Knowledge for practice*. Routledge.
- Humphrey, N. (1997). Varieties of altruism – And the common ground between them. *Social Research*, 58(7), 199–209.
- Ikkink, K. K., Van Tilburg, T., & Knipscheer, K. C. P. M. (1999). Perceived instrumental support exchanges in relationships between elderly parents and their adult children: Normative and structural explanations. *Journal of Marriage and the Family*, 61(4), 831. <https://doi.org/10.2307/354006>
- Institute, J. B. (2011). *Joanna Briggs Institute reviewers’ manual: 2011 edition Adelaide, South Australia*. University of Adelaide.
- Johnson, M. P., Caughlin, J. P., & Huston, T. L. (1999). The tripartite nature of marital commitment: Personal, moral, and structural reasons to stay married. *Journal of Marriage and the Family*, 61(1), 160–177. <https://doi.org/10.2307/353891>

- Jones, P. S., Zhang, X. E., Jaceldo-Siegl, K., & Meleis, A. I. (2002). Caregiving between two cultures: An integrative experience. *Journal of Transcultural Nursing*, 13(3), 202–209. <https://doi.org/10.1177/10459602013003009>
- Jones, P. S., Zhang, X. E., & Meleis, A. I. (2003). Transforming vulnerability. *Western Journal of Nursing Research*, 25(7), 835–853. <https://doi.org/10.1177/0193945903256711>
- Kanfer, R., Chen, G., & Pritchard, R. D. (2008). *Work motivation: Past, present and future*. Routledge.
- Kao, H. F., & Stuijbergen, A. K. (1999). Family experiences related to the decision to institutionalize an elderly member in Taiwan: An exploratory study. *Social Science & Medicine*, 49(8), 1115–1123. [https://doi.org/10.1016/S0277-9536\(99\)00211-7](https://doi.org/10.1016/S0277-9536(99)00211-7)
- Kavanagh, K. H., & Kennedy, P. H. (1992). *Promoting cultural diversity: Strategies for health care professionals*. Sage.
- Kellett, U. M. (1999). Searching for new possibilities to care: A qualitative analysis of family caring involvement in nursing homes. *Nursing Inquiry*, 6(1), 9–16. <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=107207839&site=ehost-live>. <https://doi.org/10.1046/j.1440-1800.1999.00003.x>
- Khalaila, R., & Litwin, H. (2012). Modernisation and filial piety among traditional family care-givers: A study of Arab-Israelis in cultural transition. *Ageing and Society*, 32(5), 769–789. <https://doi.org/10.1017/S0144686X11000572>
- Kietzman, K. G., Benjamin, A. E., & Matthias, R. E. (2013). Whose choice? Self-determination and the motivations of paid family and friend caregivers. *Journal of Comparative Family Studies*, 44(4), 519–540. <https://search-proquest-com.ezproxy.bangor.ac.uk/docview/1544981790?accountid=14874>. <https://doi.org/10.3138/jcfs.44.4.519>
- Kim, J. H., & Theis, S. L. (2000). Korean American caregivers: Who are they? *Journal of Transcultural Nursing*, 11(4), 264–273. <https://doi.org/10.1177/104365960001100404>
- Kim, Y. (2009). Korean-American family postcaregivers on dementia caregiving: A phenomenological inquiry. *Journal of Gerontological Social Work*, 52(6), 600–617. <https://doi.org/10.1080/01634370903048352>
- Knight, B. G., & Sayegh, P. (2010). Cultural values and caregiving: The updated sociocultural stress and coping model. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 65(1), 5–13. <https://doi.org/10.1093/geronb/gbp096>
- Knight, L., Hosegood, V., & Timaeus, I. M. (2016). Obligation to family during times of transition: Care, support and the response to HIV and AIDS in rural South Africa. *AIDS Care*, 28(sup4), 18–29. <https://doi.org/10.1080/09540121.2016.1195486>
- Kodwo-Nyameazea, Y., & Nguyen, P. V. (2008). Immigrants and long-distance elder care: An exploratory study. *Ageing International*, 32(4), 279–297. <https://doi.org/10.1007/s12126-008-9013-4>
- Kong, E. H., Deatrick, J. A., & Evans, L. K. (2010). The experiences of Korean immigrant caregivers of non-English-speaking older relatives with dementia in American nursing homes. *Qualitative Health Research*, 20(3), 319–329. <https://doi.org/10.1177/1049732309354279>
- Kooiker, S., de Jong, A., Verbeek-Oudijk, D., & de Boer, A. (2019). Toekomstverkenning mantelzorg aan ouderen in 2040.
- Kramer, B. J., & Thompson, E. H. (2002). *Men as caregivers*. Prometheus Books.
- Kristanti, M. S., Effendy, C., Utarini, A., Vernooij-Dassen, M., & Engels, Y. (2019). The experience of family caregivers of patients with cancer in an Asian country: A grounded theory approach. *Palliative Medicine*, 33(6), 676–684. <https://doi.org/10.1177/0269216319833260>
- Kuşçu, M. K., Dural, U., Yaşa, Y., Kiziltoprak, S., & Önen, P. (2009). Decision pathways and individual motives in informal caregiving during cancer treatment in Turkey. *European Journal of Cancer Care*, 18(6), 569–576. <https://doi.org/10.1111/j.1365-2354.2007.00900.x>
- Lauritzen, J., Bjerrum, M. B., Pedersen, P. U., & Sørensen, E. E. (2019). Support groups for carers of a person with dementia who lives at home: A focused ethnographic study. *Journal of Advanced Nursing*, 75(11), 2934–2942. <https://doi.org/10.1111/jan.14151>
- Lee, H., Lee, J. E. J. J.-E., & Lee, J. E. J. J.-E. (2019). Bereaved families' experiences of end-of-life care at home for older adults with non-cancer in South Korea. *Journal of Community Health Nursing*, 36(1), 42–53. <https://doi.org/10.1080/07370016.2018.1554768>
- Leichtenritt, R. D., Schwartz, V., & Rettig, K. D. (2004). The lived experiences of Israeli Arab Moslems who are caring for a relative with cognitive decline. *International Journal of Aging & Human Development*, 59(4), 363–389. doi:<https://doi.org/10.2190/YQAN-6KVA-7HPK-RX2C>
- Leonard, R., & Johansson, S. (2008). Policy and practices relating to the active engagement of older people in the community: A comparison of Sweden and Australia. *International Journal of Social Welfare*, 17(1), 37–45. <https://doi.org/10.1111/j.1468-2397.2007.00497.x>
- Leventhal, H., Brissette, I., & Leventhal, E. A. (2003). The common-sense model of self-regulation of health and illness. In L. D. Cameron, & H. Leventhal (Eds.), *The self-regulation of health and illness behaviour* (pp. 42–65). Routledge.
- Lewin, S., Bohren, M., Rashidian, A., Munthe-Kaas, H., Glenton, C., & Colvin, C. J. (2018). Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 2: How to make an overall CERQual assessment of confidence and create a Summary of Qualitative Findings table. *Implementation Science*, 13(Suppl 1). Article number: 2. <https://doi.org/10.1186/s13012-017-0689-2>
- Lewis, M. B., Curtis, M. P., & Saucier Lundy, K. (1995). He calls me his angel of mercy: The experience of caring for elderly parents in the home. *Holistic Nursing Practice*, 13, 54–65. Article number: 10. <https://doi.org/10.1097/00004650-199507000-00008>

- Lewis, S. (1997). 'Family friendly' employment policies: A route to changing organizational culture or playing about at the margins? *Gender, Work & Organization*, 4(1), 13–23. <https://doi.org/10.1111/1468-0432.00020>
- Li, L. W., Long, Y., Essex, E. L., Sui, Y., & Gao, L. (2012). Elderly Chinese and their family caregivers' perceptions of good care: A qualitative study in Shandong, China. *Journal of Gerontological Social Work*, 55(7), 609–625. <https://doi.org/10.1080/01634372.2012.703165>
- Lieberman, M. A., & Fisher, L. (1999). The effects of family conflict resolution and decision making on the provision of help for an elder with Alzheimer's disease. *The Gerontologist*, 39(2), 159–166. <https://doi.org/10.1093/geront/39.2.159>
- Lin, M. C., Macmillan, M., & Brown, N. (2012). A grounded theory longitudinal study of carers' experiences of caring for people with dementia. *Dementia*, 11(2), 181–197. <https://doi.org/10.1177/1471301211421362>
- Lind, E. A., & Tyler, T. R. (1988). *Critical issues in social justice. The social psychology of procedural justice*. Plenum Press. <https://doi.org/10.1007/978-1-4899-2115-4>
- List of Developing Countries. (2018). *List of developing countries*. The International Society of Gynecological Endocrinology. <https://isge2018.isgesociety.com/registration/list-of-developing-countries/>
- Lyonette, C., & Yardley, L. (2003). The influence on carer wellbeing of motivations to care for older people and the relationship with the care recipient. *Ageing and Society*, 23(4), 487–506. <https://doi.org/10.1017/S0144686X03001284>
- Mahilall, R. (2006). Motivations and expectations of a locally specific group of volunteer home based carers serving people with HIV/AIDS in the Mariannhill region.
- Mars, D. G. (2015). *The lived experience of African American informal caregivers of a family member with Alzheimer's disease and related dementias*. Hampton University.
- McDermott, E., & Mendez-Luck, C. A. (2018). The processes of becoming a caregiver among Mexican-origin women: A cultural psychological perspective. *Sage Open*, 8(2). <https://doi.org/10.1177/2158244018771733>
- McDonnell, J. R., Abell, N., & Miller, J. (1991). Family members' willingness to care for people with AIDS: A psychosocial assessment model. *Social Work*, 36(1), 43–53. <https://doi.org/10.1093/sw/36.1.43>
- McDonnell, E., & Ryan, A. A. (2014). The experience of sons caring for a parent with dementia. *Dementia*, 13(6), 788–802. <https://doi.org/10.1177/1471301213485374>
- Mendez-Luck, C., & Anthony, K. P. (2016). Marianismo and caregiving role beliefs among U.S.-born and immigrant Mexican women. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences*, 71(5), 926–935. <https://doi.org/10.1093/geronb/gbv083>
- Merrill, D. M. (1996). Conflict and cooperation among adult siblings during the transition to the role of filial caregiver. *Hispanic Journal of Behavioral Sciences*, 13(3), 399–413. <https://doi.org/10.1177/07399863870092005>
- Meyer, O. L., Nguyen, K. H., Dao, T. N., Vu, P., Arian, P., & Hinton, L. (2015). The sociocultural context of caregiving experiences for Vietnamese dementia family caregivers. *Asian American Journal of Psychology*, 6(3), 263–272. <https://doi.org/10.1037/aap0000024>
- Mok, E., Chan, F., Chan, V., & Yeung, E. (2003). Family experience caring for terminally ill patients with cancer in Hong Kong. *Cancer Nursing*, 26(4), 267–275. <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=106880188&site=ehost-live>. <https://doi.org/10.1097/00002820-200308000-00003>
- Morgan, D. G., & Laing, G. P. (1991). The diagnosis of Alzheimer's disease: Spouse's perspectives. *Qualitative Health Research*, 1(3), 370–387. doi:<https://doi.org/10.1177/104973239100100306>
- Muoghalu, C. O., & Jegede, S. A. (2010). The role of cultural practices and the family in the care for people living with HIV/AIDS among the Igbo of Anambra State, Nigeria. *Social Work in Health Care*, 49(10), 981–1006. <https://doi.org/10.1080/00981389.2010.518885>
- Murphy, M. R. (2005). *Positive aspects of family caregiving of patients with Alzheimer's disease: A qualitative study*. Our Lady of the Lake University in Texas. <https://search.proquest.com/docview/220297257?accountid=12834>
- Neufeld, A., & Harrison, M. J. (1998). Men as caregivers: Reciprocal relationships or obligation? *Journal of Advanced Nursing*, 28(5), 959–968. <https://doi.org/10.1046/j.1365-2648.1998.00818.x>
- Ng, H. Y., Griva, K., Lim, H. A., Tan, J. Y. S., & Mahendran, R. (2016). The burden of filial piety: A qualitative study on caregiving motivations amongst family caregivers of patients with cancer in Singapore. *Psychology & Health*, 31(11), 1293–1310. <https://doi.org/10.1080/08870446.2016.1204450>
- Nkongho, N. O., & Archbold, P. G. (1995). Reasons for caregiving in African American families. *Journal of Cultural Diversity*, 2(4), 116–123.
- Noyes, J., & Lewin, S. (2011). *Supplemental guidance on selecting a method of qualitative evidence synthesis, and integrating qualitative evidence with Cochrane intervention reviews*. Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions.
- Öhman, M., & Söderberg, S. (2004). The experiences of close relatives living with a person with serious chronic illness. *Qualitative Health Research*, 14(3), 396–410. <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=106760470&site=ehost-live>. <https://doi.org/10.1177/1049732303261692>
- Opie, A. (1994). The instability of the caring body: Gender and caregivers of confused older people. *Social Psychological and Personality Science*, 1994(4), 31–50. <https://doi.org/10.1177/1948550611411929>
- Øygdard, G. W. (2017). The influence of institutional discourses on the work of informal carers: An institutional ethnography from the perspective of informal carers. *BMC Health Services Research*, 17(1), 1–12. <https://doi.org/10.1186/s12913-017-2591-7>

- Pang, R. C. K., & Lee, D. T. F. (2019). Finding positives in caregiving: The unique experiences of Chinese spousal caregivers of persons with young-onset dementia. *Dementia*, 18(5), 1615–1628. <https://doi.org/10.1177/1471301217724026>
- Park, H. J. (2015). Legislating for filial piety: An indirect approach to promoting family support and responsibility for older people in Korea. *Journal of Aging & Social Policy*, 27(3), 280–293. <https://doi.org/10.1080/08959420.2015.1024536>
- Park, M. (2012). Filial piety and parental responsibility: An interpretive phenomenological study of family caregiving for a person with mental illness among Korean immigrants. *BMC Nursing*, 11(1), 28–35. <https://doi.org/10.1186/1472-6955-11-28>
- Parveen, S., & Morrison, V. (2012). Predicting caregiver gains: A longitudinal study. *British Journal of Health Psychology*, 17(4), 711–723. <https://doi.org/10.1111/j.2044-8287.2012.02067.x>
- Parveen, S., Morrison, V., & Robinson, C. A. (2011). Ethnic variations in the caregiver role: A qualitative study. *Journal of Health Psychology*, 16(6), 862–872. <https://doi.org/10.1177/1359105310392416>
- Parveen, S., Morrison, V., & Robinson, C. A. (2013). Ethnicity, familism and willingness to care: Important influences on caregiver mood? *Aging & Mental Health*, 17(1), 115–124. <https://doi.org/10.1080/13607863.2012.717251>
- Parveen, S., Morrison, V., & Robinson, C. A. (2014). Does coping mediate the relationship between familism and caregiver outcomes? *Aging & Mental Health*, 18(2), 255–259. <https://doi.org/10.1080/13607863.2013.827626>
- Pelusi, J. L. (1999). *Cancer survivorship: The other side. The lived experience of partners of long-term breast cancer survivors (quality of life, coping)*. *Cancer Survivorship. The Other Side. The Lived Experience of Partners of Long-term Breast Cancer Survivors*. University of Arizona. <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=109842980&site=ehost-live>.
- Pickard, L. (2015). A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032. *Ageing and Society*, 35(1), 96–123. <https://doi.org/10.1017/S0144686X13000512>
- Pierce, L. L. (2001). Caring and expressions of stability by urban family caregivers of persons with stroke within African American family systems. *Rehabilitation Nursing*, 26(3), 100. <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=12035690&site=ehost-live>. <https://doi.org/10.1002/j.2048-7940.2001.tb02213.x>
- Piotrowska, E. Z. (2015). Problemy społeczne rodzin opiekujących się swoimi bliskimi w terminalnym okresie choroby nowotworowej. *Med Paliatywna*, 7(1), 45–57.
- Qadir, F., Gulzar, W., Haqqani, S., & Khalid, A. (2013). A pilot study examining the awareness, attitude, and burden of informal caregivers of patients with dementia. *Care Management Journals*, 14(4), 230–240. <https://doi.org/10.1891/1521-0987.14.4.230>
- Qiu, X., Sit, J. W. H., & Koo, F. K. (2018). The influence of Chinese culture on family caregivers of stroke survivors: A qualitative study. *Journal of Clinical Nursing*, 27(1-2), e309–e319. <https://doi.org/10.1111/jocn.13947>
- Quinn, C. (2009). *Relationships, motivations and meanings in informal caregiving for people with dementia*. Bangor University.
- Quinn, C., Clare, L., & Woods, R. T. (2010). The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: A systematic review. *International Psychogeriatrics*, 22(1), 43–55. <https://doi.org/10.1017/S1041610209990810>
- Revenson, T., Griva, K., Luszczynska, A., Morrison, V., Panagopoulou, E., & Vilchinsky, N. (2016). *Caregiving in the illness context*. Springer.
- Rivera, J., Bermejo, F., Franco, M., Morales-González, J. M., & Benito-León, J. (2009). Understanding care of people with dementia in Spain: Cohabitation arrangements, rotation and rejection to long term care institution. *International Journal of Geriatric Psychiatry*, 24(2), 142–148. <https://doi.org/10.1002/gps.2081>
- Rokeach, M. (2008). *Understanding human values*. Simon and Schuster.
- Russell, R. (2001). In sickness and in health a qualitative study of elderly men who care for wives with dementia. *Journal of Aging Studies*, 15(4), 351–367. [https://doi.org/10.1016/S0890-4065\(01\)00028-7](https://doi.org/10.1016/S0890-4065(01)00028-7)
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68–78. <https://doi.org/10.1037/0003-066X.55.1.68>
- Sand, L., Olsson, M., & Strang, P. (2010). What are motives of family members who take responsibility in palliative cancer care? *Mortality*, 15(1), 64–80. doi:<https://doi.org/10.1080/13576270903537690>
- Sasat, S. (1998). *Caring for dementia in Thailand: A study of family care for demented elderly relatives in Thai Buddhist society*. University of Hull.
- Schulz, R., Biegel, D., Morycz, R., & Visintainer, P. (1989). Psychological paradigms for understanding caregiving. In E. Light, & B. D. Lebowitz (Eds.), *Alzheimer's disease treatment and family stress: Directions for research* (pp. 106–121). U.S. Department of Health and Human Services, National Institute of Mental Health.
- Schwarzkopf, L., Menn, P., Leidl, R., Wunder, S., Mehlig, H., & Marx, P. (2012). Excess costs of dementia disorders and the role of age and gender-an analysis of German health and long-term care insurance costs claims data. *BMC Health Services Research*, 12(1), 165. <https://doi.org/10.1186/1472-6963-12-165>
- Seddon, D., & Robinson, C. (2015). Carer assessment: Continuing tensions and dilemmas for social care practice. *Health & Social Care in the Community*, 23(1), 14–22. <https://doi.org/10.1111/hsc.12115>

- Sheu, S. (1997). *Filial piety (Hsiao) and filial caregiving experiences of Chinese families in the San Francisco Bay area*. University of California.
- Silverstein, M., Gans, D., & Yang, F. M. (2006). Intergenerational support to aging parents: The role of norms and needs. *Journal of Family Issues*, 27(8), 1068–1084. <https://doi.org/10.1177/0192513X06288120>
- Sims-Gould, J., & Martin-Matthews, A. (2008). Themes in family care-giving: Implications for social work practice with older adults. *British Journal of Social Work*, 38(8), 1572–1587. <https://doi.org/10.1093/bjsw/bcm073>
- Skills for Care. (2018). *Using conversations to assess and plan people's care and support. The principles of conversational assessment*. Leeds. <https://www.skillsforcare.org.uk/Documents/Leadership-and-management/Workforce-commissioning/Conversational-assessment/Using-conversations-to-assess-and-plan-peoples-care-and-support.pdf>
- Spitzer, D., Neufeld, A., Harrison, M., Hughes, K., & Stewart, M. (2003). Caregiving in transnational context: "My wings have been cut; where can I fly?". *Gender & Society*, 17(2), 267–286. <https://doi.org/10.1177/0891243202250832>
- Stajduhar, K. I., Funk, L., Toye, C., Grande, G. E., Aoun, S., & Todd, C. J. (2010). Part 1: Home-based family caregiving at the end of life: A comprehensive review of published quantitative research (1998–2008). *Palliative Medicine*, 24(6), 573–593. <https://doi.org/10.1177/0269216310371412>
- Stajduhar, K. I., Martin, W. L., Barwich, D., & Fyles, G. (2008). Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nursing*, 31(1), 77–85. <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=106012784&site=ehost-live>. <https://doi.org/10.1097/01.NCC.0000305686.36637.b5>
- Statham, J. (2003). *A day at a time: A study of unsupported family carers of older people*. University of Glasgow.
- Sterritt, P. F., & Pokorny, M. E. (1998). African-American caregiving for a relative with Alzheimer's disease. *Geriatric Nursing*, 19(3), 127–128. [https://doi.org/10.1016/S0197-4572\(98\)90056-8](https://doi.org/10.1016/S0197-4572(98)90056-8)
- Strumpf, N. E., Glicksman, A., Goldberg-Glen, R. S., Fox, R. C., & Logue, E. H. (2001). Caregiver and elder experiences of Cambodian, Vietnamese, Soviet Jewish, and Ukrainian refugees. *International Journal of Aging & Human Development*, 53(3), 233–252. <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=106680721&site=ehost-live>. <https://doi.org/10.2190/PXUG-J0T8-DGUK-08MD>
- Sung, K. (1994). A cross-cultural comparison of motivations for parent care: The case of Americans and Koreans. *Journal of Ageing Studies*, 8(2), 195–209. [https://doi.org/10.1016/S0890-4065\(05\)80006-4](https://doi.org/10.1016/S0890-4065(05)80006-4)
- Tagigiku, S. K., Brubaker, T. H., & Hennon, C. B. (1993). A contextual model of stress among parent caregivers of gay sons with AIDS. *AIDS Education and Prevention*, 5(1), 25–42.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(1), 45. <https://doi.org/10.1186/1471-2288-8-45>
- Tretteteig, S., Vatne, S., & Rokstad, A. M. M. (2017). Meaning in family caregiving for people with dementia: A narrative study about relationships, values, and motivation, and how day care influences these factors. *Journal of Multidisciplinary Healthcare*, 10, 445–455. <https://doi.org/10.2147/JMDH.S151507>
- Tretteteig, S., Vatne, S., Rokstad, A. M. M., & Rokstad, A. M. M. (2017). The influence of day care centres designed for people with dementia on family caregivers – A qualitative study. *BMC Geriatrics*, 17(1), 1–11. <https://doi.org/10.1186/s12877-016-0403-2>
- Van Sjaak Geest, D. E. R. (2002). Respect and reciprocity: Care of elderly people in rural Ghana. *Journal of Cross-Cultural Gerontology*, 17(1), 3–31. <https://doi.org/10.1023/A:1014843004627>
- van Wezel, N., Francke, A. L., Kayan-Acun, E., Devillé, L. J. M., van Grondelle, N. J., & Blom, M. M. (2016). Family care for immigrants with dementia: The perspectives of female family carers living in the Netherlands. *Dementia*, 15(1), 69–84. <https://doi.org/10.1177/1471301213517703>
- Vellone, E., Sansoni, J., & Cohen, M. Z. (2002). The experience of Italians caring for family members with Alzheimer's disease. *Journal of Nursing Scholarship*, 34(4), 323–329. <https://doi.org/10.1111/j.1547-5069.2002.00323.x>
- Wallhagen, M. I., & Yamamoto-Mitani, N. (2006). The meaning of family caregiving in Japan and the United States: A qualitative comparative study. *Journal of Transcultural Nursing*, 17(1), 65–73. Available: <http://ezproxy.bangor.ac.uk/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=rzh&AN=106325259&site=ehost-live>. <https://doi.org/10.1177/1043659605281979>
- Wallroth, V. (2016). *Men do care! A gender-aware and masculinity-informed contribution to caregiving scholarship*. Linköping University.
- Weinland, J. A. (2009). The lived experience of informal African American male caregivers. *American Journal of Men's Health*, 3(1), 16–24. <https://doi.org/10.1177/1557988307305916>
- Wells, Y. D., & Johnson, T. M. (2001). Impact of parental divorce on willingness of young adults to provide care for parents in the future. *Journal of Family Studies*, 7(2), 160–170. <https://doi.org/10.5172/jfs.7.2.160>
- Wiles, J. L. (2002). *Performative production of homes as places for care: Narrative experiences of people caring informally for seniors in Kingston*. Queen's University.
- Williams, K. L., Morrison, V., & Robinson, C. A. (2014). Exploring caregiving experiences: Caregiver coping and making sense of illness. *Aging & Mental Health*, 18(5), 600–609. <https://doi.org/10.1080/13607863.2013.860425>
- Woolfolk, A. (2013). *Educational psychology*. Pearson Education.
- Yamamoto, N., & Wallhagen, M. I. (1997). The continuation of family caregiving in Japan. *Journal of Health and Social Behavior*, 38(2), 164–176. <https://doi.org/10.2307/2955423>

- Yeo, G., UyenTran, J. N., Hikoyeda, N., & Hinton, L. (2002). Conceptions of dementia among Vietnamese American caregivers. *Journal of Gerontological Social Work*, 36(1-2), 131–152. <https://doi.org/10.1300/J083v36n01>
- Zarzycki, M., & Morrison, V. (2021). Getting back or giving back: Understanding caregiver motivations and willingness to provide informal care. *Health Psychology and Behavioral Medicine*, 9(1), 636–661. <https://doi.org/10.1080/21642850.2021.1951737>
- Zhang, J., & Lee, D. T. F. (2019). Meaning in stroke family caregiving in China: A phenomenological study. *Journal of Family Nursing*, 25(2), 260–286. <https://doi.org/10.1177/1074840719841359>