Bangor University

DOCTOR OF PHILOSOPHY

Why do they care? Using mixed methods to explore adult informal caregivers’ motivations and willingness to provide care

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Why do they care? Using mixed methods to explore adult informal caregivers’ motivations and willingness to provide care

Ph.D. Thesis Appendices

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Appendices accompanying the thesis submitted to Bangor University in fulfilment of the requirements for the degree of Doctor of Philosophy (Ph.D.) in Psychology

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Appendices

Appendix Page

Appendix 1 Meta-synthesis (Chapters 2 & 3)

Appendix 2 Meta-ethnography (Chapter 4)

Appendix 3 Qualitative study (Chapter 5)

Appendix 4 Quantitative study (Chapters 6 & 7)

A1 Appendix - Title and Abstract Screening Tools

Title and Abstract Screening Tool

Primary research question:

What are the determinants of motivations and willingness to provide care in informal caregiving?

Secondary research objectives:

The aim of this review is to systematically identify, extract, appraise and explore the existing literature on informal caregivers' motivations to provide care and willingness to perform caregiving. The specific objectives are to:

a) Identify existing literature on motivations to provide care and willingness to provide care within the context of informal caregiving.
b) Critically appraise and explore existing research regarding the subject.
c) Explore the personal, social, ethnic and cultural factors (determinants) underlying caregivers' motivations and willingness to provide care.
d) Explore the differences or similarities between the influence of factors on motivations to provide care and willingness to provide care among informal caregivers.
e) Identify whether and what further research is needed.
f) Identify implications for future policy and practice development.

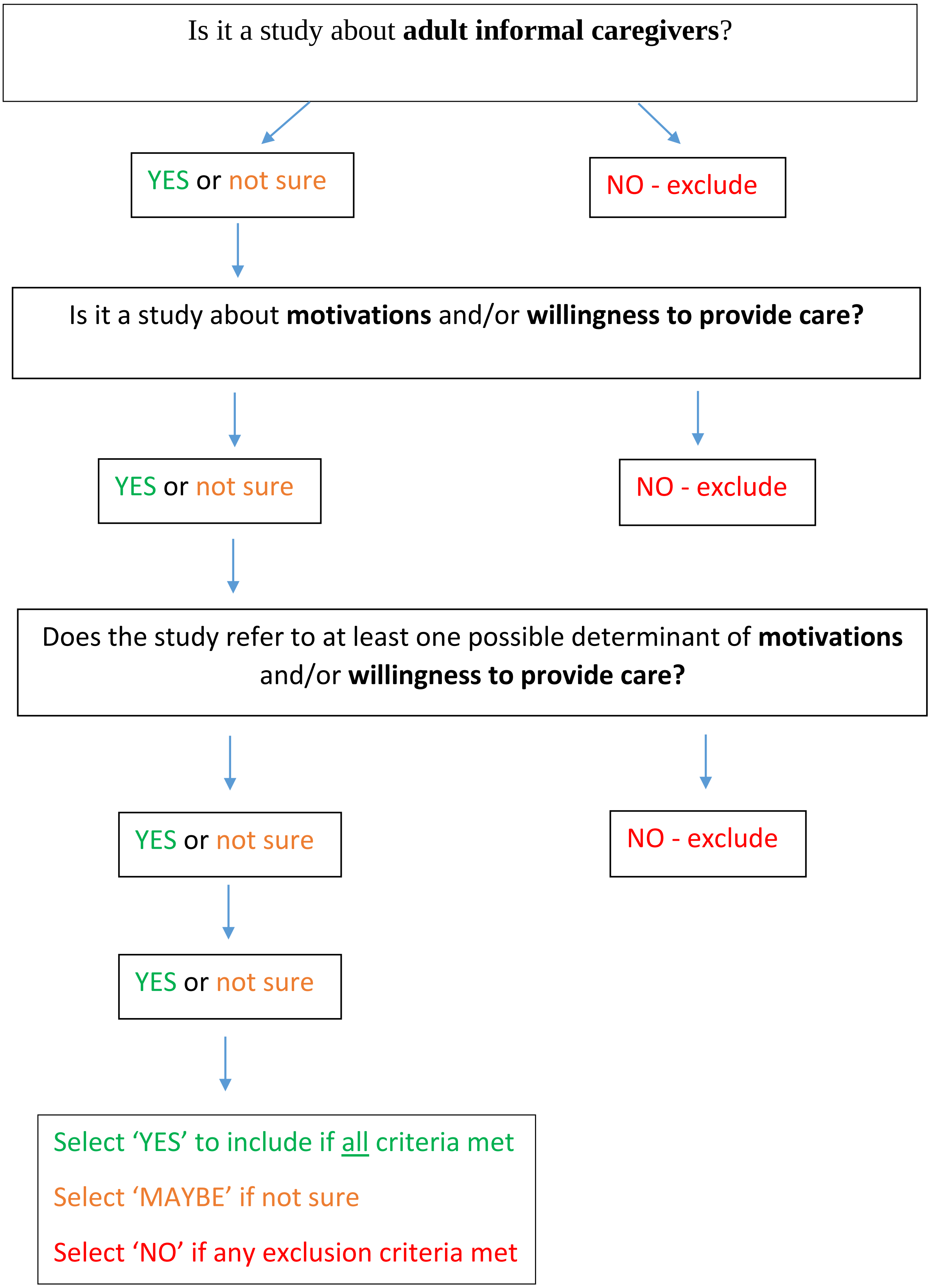
Questions – key elements

Population (P)	**Include:** **Studies concerning adult informal caregivers** Informal caregiving refers to physical and psychological support, mostly unpaid, for a family member or friend, beyond what is typical of that relationship. No restrictions applied to caregiver relationship type (e.g., spouse/non spouse), care recipient's age, gender or care recipient's diagnosis. **OR** **Studies about patients/care recipients where their adult caregivers were also examined** Dyadic studies of both care recipients (patients) and caregivers **Studies about people who were informal caregivers in their past** People who were informal caregivers in their past but are not necessarily carers actually (i.e. it is not specified explicitly)
	Exclude: Young caregivers, adult caregivers of children, formal caregivers (e.g., professional carers, nurse practitioners, practice nurses, physicians, physio/occupational therapists, multi-disciplinary other professional care staff); people who are hypothesizing about the possible informal caregiving in the future and have not been identified as carers; service volunteers

Concepts 1 (C1)	**Include:** Studies exploring motivations to provide care and/or willingness to provide care Studies examining reasons of care provision, motives of caregiving, caregiving obligation(s) and duties (e.g., filial obligation, filial piety), actual willingness to provide care
	Exclude: no data pertaining to any of the key concepts of motivations or willingness to provide care; studies examining only hypothetical willingness to provide care (e.g., in the future) and (future) willingness to care *again* (usually after transition)
Concepts 2 (C2)	**Include:** Studies referring to (personal, social, ethnic and cultural) determinants of motivations to provide care and willingness to provide care. Study based on one determinant (e.g., gender) is sufficient to be included for further screening. Relevant studies investigating influence of determinants on key concepts C1 (motivations to provide care or willingness to provide care). Studies where determinants are mediators or moderators of the relationship in which one of the variables derives from the key concept C1 (motivation or willingness to provide care).
	Exclude: Studies that are *only* focused on the impact of motivations to provide care and willingness to provide care on caregiver outcomes; no data pertaining to key concepts
Study type	**Include:** Any study design, including original research, review articles, case studies, dissertations, opinions or commentaries and especially theory-rich papers with potential mechanisms, process evaluations, etc.
	Exclude: N/A (broad evidence included for theoretical richness)

NOTES FOR SCREENING:

- Study must meet all criteria to be included i.e. it must be about adult informal caregivers, motivations to provide care and/or willingness to provide care, possible determinants of the previous concepts.
- If a study meets any of exclusion criteria, it is excluded.
- If in a doubt, the study is included under condition of further check of the full paper.


Is it a study about **adult informal caregivers**?
YES or not sure
NO - exclude
Is it a study about **motivations** and/or **willingness to provide care?**
YES or not sure
NO - exclude
Does the study refer to at least one possible determinant of **motivations** and/or **willingness to provide care?**
YES or not sure
NO - exclude
YES or not sure
Select 'YES' to include if all criteria met
Select 'MAYBE' if not sure
Select 'NO' if any exclusion criteria met

A2 Appendix - PRISMA (2020) Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3-4
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	4
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	5-6
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	5, 6-7
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	6, 7
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	5, 7-8
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	6-8
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	5-6
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	8-9
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	7-8
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	N/A
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	5-9
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	5-9
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	5-9
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	8-9
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	9
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	8, 12
Reporting bias	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	11, 12

A2 Appendix - PRISMA (2020) Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
assessment			
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	12
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	9
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	9, 11
Study characteristics	17	Cite each included study and present its characteristics.	9-11
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	11,12
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	11,12
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	12-26
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	9, 12
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	9, 12
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	9, 11, 12
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	9, 12
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	27-28
	23b	Discuss any limitations of the evidence included in the review.	31
	23c	Discuss any limitations of the review processes used.	31
	23d	Discuss implications of the results for practice, policy, and future research.	28-31
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	5
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	5
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	5
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	1
Competing interests	26	Declare any competing interests of review authors.	1

A2 Appendix - PRISMA (2020) Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	5-9

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

A3 Appendix - CASP qualitative checklist for the meta-synthesis demonstrating how each study addressed the CASP qualitative checklist (2014) quality aspects

Study	**CASP Checklist Questions**										**Methodological quality summary**
	1	2	3	4	5	6	7	8	9	10	
	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?	
Albinsson and Strang (2003)	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	High
Alonso et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
Anngela-Cole and Busch (2011)	✓	✓	✗	✓	✓	?	?	✓	✓	✓	Moderate
de Leon Arabit (2005)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Aronson (1992)	✓	✓	✓	?	✗	?	?	?	?	?	Low
Arpanantikul (2018)	✓	✓	✓	✓	?	✓	✓	✓	✓	✓	High
Asahara et al. (2002)	✓	✓	?	?	✗	?	?	✗	?	?	Low
Almeida et al. (2018)	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	High
Bäckström and Sundin (2010)	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	High
Bashir (2014)	✓	✓	✓	✓	?	?	?	?	✓	✓	Moderate
Boeije et al. (2003)	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	High

Browne Sehy (1998)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Bryant and Lim (2013)	✓	✓	✓	?	✓	✓	✓	✓	✓	✓	High
Cahill (1999)	✓	✓	✓	✓	?	?	?	✓	?	✓	Moderate
Cash et al. (2013)	✓	✓	✓	?	✓	?	?	✓	✓	✓	Moderate
Chao and Roth (2000)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Clark and Huttlinger (1998)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Donorfio and Kellett (2006)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Donovan and Williams (2015)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Dumit et al. (2015)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Dunér (2010)	✓	✓	✓	✓	✓	?	✗	✓	✓	✓	Moderate
Erickson (2002)	✓	✓	✓	✓	?	?	?	✓	✓	✓	Moderate
Foster (2012)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
Funk (2012)	✓	✓	✓	✓	?	?	?	✓	✓	✓	Moderate
Gerdner et al. (2007)	✓	✓	✓	?	✓	?	✓	✓	✓	✓	High
Globerman (1996)	?	✓	✓	✓	✓	✓	?	✓	✓	✓	High
Guberman et al. (1992)	✓	✓	✓	✓	?	?	?	✗	✓	✓	Moderate
Gurayah (2015)	✓	✓	✓	✓	✓	?	✓	?	?	?	Moderate
Han et al. (2008)	✓	✓	✓	?	✓	?	✓	✓	✓	✓	High

Hanyok et al. (2009)	✓	✓	✓	?	?	?	✓	?	?	✗	Low
Harris (1998)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Harris and Long (1999)	✓	✓	✓	✓	✓	?	?	✗	✓	✓	Moderate
Hinton et al. (2008)	✓	✓	✓	✓	✓	?	?	?	✓	✓	Moderate
Ho et al. (2003)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Holroyd (2001)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	Moderate
Holroyd (2005)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Holroyd (2003)	✓	✓	✓	✓	?	?	?	✗	?	?	Low
Hsu and Shyu (2003)	✓	✓	✓	✓	?	✓	?	✓	✓	✓	High
Hsueh et al. (2008)	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	High
Jones et al. (2003)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Jones et al. (2002)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Kao and Stuifbergen (1999)	✓	✓	✓	✓	✓	?	?	?	✓	✓	Moderate
Kellett (1999)	✓	✓	✓	?	?	?	✓	✓	✗	✗	Low
Kietzman et al. (2013)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Kim and Theis (2000)	✓	✓	✓	✓	✓	?	?	?	?	?	Moderate
Kim (2009)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Knight et al. (2016)	✓	✓	✓	✓	?	✓	✓	✗	✓	?	Moderate

Kodwo-Nyameazea and Nguyen (2008)	✓	✓	✓	✓	?	✓	?	✓	✓	✓	High
Kong et al. (2010)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Kristanti et al. (2019)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Kuşçu et al. (2009)	✓	✓	✓	✓	?	?	?	?	✓	?	Moderate
Lauritzen et al. (2019)	✓	✓	✓	✓	?	✓	✓	✓	✓	?	High
Lee et al. (2019)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Leichtentritt et al. (2004)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Lewis et al. (1995)	✓	✓	✓	✓	?	?	?	✓	?	?	Moderate
Li et al. (2012)	✓	✓	✓	✓	✓	✓	?	✓	✓	✓	High
Lin et al. (2012)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Mahilall (2006)	✓	✓	✓	✓	✓	✓	✓	✓	?	✓	High
Mars (2015)	✓	✓	?	✓	?	✓	✓	?	?	?	Moderate
McDermott and Mendez-Luck (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
McDonell et al. (1991)	✓	?	?	✗	✗	?	?	✗	✓	?	Low
McDonnell and Ryan (2014)	✓	✓	✓	✓	?	?	✓	✓	✓	✓	High
Mendez-Luck and Anthony (2016)	✓	✓	✓	✓	✓	?	✓	✓	?	?	Moderate
Merrill (1996)1	✓	✓	?	✓	✓	?	?	?	?	?	Moderate

Meyer et al. (2015)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Mok et al. (2003)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Morgan and Laing (1991)	✓	✓	✓	✕	✓	**?**	✓	✓	✓	**?**	Moderate
Muoghalu and Jegede (2010)	✓	✓	**?**	**?**	✓	**?**	**?**	**?**	✓	**?**	Moderate
Murphy (2005)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Neufeld and Harrison (1998)	✓	✓	✓	✓	✓	✓	✓	**?**	✓	✓	High
Ng et al. (2016)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Nkongho and Archbold (1995)	✓	✓	**?**	✓	✓	**?**	**?**	✓	✓	✓	Moderate
Öhman and Söderberg (2004)	✓	✓	✓	✓	**?**	**?**	✓	✓	✓	✓	High
Opie (1994)	✓	✓	**?**	✓	**?**	**?**	**?**	✓	✓	✓	Moderate
Øydgard (2017)	✓	✓	✓	**?**	**?**	**?**	✓	✕	✓	**?**	Moderate
Pang and Lee (2019)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Park (2012)	**?**	✓	✓	✓	✓	✓	**?**	✕	✓	**?**	Moderate
Park (2015)	✓	✓	✓	**?**	**?**	**N/A**	✓	✓	✓	**?**	Moderate
Parveen et al. (2011)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Pelusi (1999)	✓	✓	**?**	✓	**?**	**?**	✓	**?**	**?**	**?**	Moderate
Pierce (2001)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	**?**	High

Piotrowska (2015)	✓	✓	?	✓	✕	?	?	✕	?	?	Low
Qadir et al. (2013)	✓	✓	✓	✓	✓	?	✓	✕	✓	✓	Moderate
Qiu et al. (2018)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Quinn (2009)	✓	✓	✓	✓	?	?	✓	✓	?	✓	Moderate
Rivera et al. (2009)	✓	✓	✓	✓	✓	?	?	?	?	?	Moderate
Russell (2001)	✓	✓	✓	✓	✓	?	?	✕	✓	✓	Moderate
Sand et al. (2010)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Sasat (1998)	✓	✓	✓	✓	✓	?	✓	?	?	?	Moderate
Sheu (1997)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
Spitzer et al. (2003)	✓	✓	✓	✓	✓	?	?	✕	✓	✓	Moderate
Stajduhar et al. (2008)	✓	✓	✓	✓	?	?	✓	?	✓	✓	Moderate
Statham (2003)	✓	✓	✓	✓	?	?	✓	✓	✓	✓	High
Sterritt and Pokorny (1998)	✓	✓	✓	✓	✓	?	?	?	✓	✓	Moderate
Strumpf et al. (2001)	✓	✓	✓	✓	?	✓	✓	?	✓	?	Moderate
Sung (1994)	✓	?	?	✓	?	?	?	?	?	?	Low
Takigiku et al. (1993)	?	✓	✕	✕	?	?	?	?	✓	?	Low
Tretteteig et al. (2017a)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
Tretteteig et al. (2017b)	✓	✓	✓	✓	✓	?	✓	✓	✓	?	High
Van Sjaak Geest (2002)	✓	✓	✓	✕	?	✓	?	?	✓	✓	Moderate

van Wezel et al. (2016)	✓	✓	✓	✓	?	?	✓	?	✓	✓	Moderate
Vellone et al. (2002)	✓	✓	✓	✓	?	?	?	✓	✓	✓	Moderate
Wallhagen and Yamamoto-Mitani (2006)	✓	✓	✓	✓	?	?	?	✓	✓	✓	Moderate
Wallroth (2016)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
Weinland (2009)	✓	✓	✓	✓	?	?	✓	✓	✓	✓	High
Wiles (2002)	✓	✓	✓	✓	?	?	?	✓	?	✓	Moderate
Williams et al. (2014)	✓	✓	✓	✓	✓	?	✓	?	✓	✓	High
Yamamoto and Wallhagen (1997)	✓	✓	✓	✓	?	?	?	✓	✓	✓	Moderate
Yeo et al. (2002)	✓	✓	✓	✓	✓	?	?	?	✓	✓	Moderate
Zhang and Lee (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High

Key:

(✓) indicates that the study was assessed as possessing the specified quality aspect

(✕) indicates that the study was assessed as lacking the specified quality aspect

(**?**) indicates that it was not possible to sufficiently assess whether the study possesses the specified quality aspect

A4 Appendix - Weight of Evidence Framework (WoE) applied in the critical appraisal of the methods of the included studies

Table Weight of Evidence Framework (WoE)

	Qualitative research
WoE A: Soundness of studies	High: Methods are transparent and detailed for data collection and analysis of the data, results are reported clearly and the interpretation of the findings is justified by the results. Moderate: Methods are reported satisfactorily (in terms of transparency and reproducibility) for data collection and analysis of the data, results are clearly reported and the interpretation of findings is at least partly justified by the results. Low: Methods are reported poorly for data collection and analysis of the data, results are reported deficiently and the interpretation of findings is not justified by the results.
WoE B: Appropriateness of study design and analysis for answering the review question	High: Focus group or interviews with participants of varied or distinguishing sociodemographics, reporting that data saturation had been reached. Extensive exploration of determinants of motivations and willingness to provide care. Moderate: Focus groups or interviews with participants of distinguishing sociodemographics, reporting that data saturation had been reached. Satisfactory exploration of determinants of motivations and willingness to provide care. Low: Focus groups or interviews. Insufficient reporting of key concepts and sociodemographics and data saturation.

WoE C: Relevance of the study focus to the review (topic, sample, population, measures, overall evidence focus)	High: Extensive exploration of differences and similarities in the influence of determinants on motivations and willingness to provide care. The sample is distinguished based on its sociodemographics (e.g., ethnic groups) or other determinant, and these are explored in relation to caregiver motives and willingness to provide care. Moderate: Satisfactory exploration of differences and similarities in the influence of determinants on motivations and willingness to provide care. The sample is not clearly distinguished based on its sociodemographics (e.g., ethnic groups) or other determinants. Low: Very poor exploration of determinants on motivations and willingness to provide care with no examination of sociodemographic determinants on the key concepts.

A5 Appendix - GRADE-CERQual Qualitative Evidence Profile - Summary of findings and assessment of confidence in analytic themes

Analytic Theme	Studies contributing to finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual rating	Comments
Contextual aspects of caregiving: Actual situational caregiving circumstances and temporal aspects of caregiving affecting the extent to which other presented themes (discerned on cultural, societal, relational and personal levels) have dominance/salience	43 [1–43]	Very minor concerns regarding methodological limitations that are unlikely to reduce confidence in the review finding. Removal of one article with low methodological quality did not change this theme.	Very minor concerns about coherence across studies that are unlikely to reduce confidence in the review finding. Varied and diverse experiences across and within studies reflect contextual and changing aspects in motivations and willingness to provide informal care.	Very minor concerns regarding data adequacy related to female caregivers with Asian and Caucasian ethnic origins. Minor or moderate concerns [few studies] for: non-Caucasian American and Black African ethnic origins; Australia and Oceania, South America, Middle East and Africa. Serious concerns about adequacy [lack of studies] pertaining to Arab ethnicity.	Very minor concerns regarding relevance related to female caregivers with Asian and Caucasian ethnic origins. Minor or moderate concerns [few studies] for: non-Caucasian American and Black African ethnic origins; Australia and Oceania, South America, Middle East and Africa. Serious concerns about relevance [lack of studies] pertaining to Arab ethnicity. Moderate concerns for the developing countries.	**High Confidence**	These findings come mainly from a caregiving population of female caregivers with Asian and Caucasian ethnic origins. Much less confidence should be acknowledged for: male caregivers; ethnicity other than Asian and Caucasian; Australia and Oceania, South America, Middle East and Africa. The theme moderately reflected in the developing countries.
The nature of relationship: Motivations and willingness to provide care come from relational aspects, including emotions, cognitions	103 [1–103]	Very minor concerns regarding methodological limitations that are unlikely to reduce confidence in the review finding. Removal of three articles with low methodological quality did not change this theme.	No or very minor concerns about coherence across studies that are unlikely to reduce confidence in the review finding. Relational determinants of motivations and	No or very minor concerns regarding data adequacy related to female and male caregivers with Asian, Caucasian and non-Caucasian American ethnicities. Minor or moderate concerns	No or very minor concerns regarding relevance related to female and male caregivers with Asian, Caucasian and non-Caucasian American ethnicities. Minor or moderate concerns [few	**High Confidence**	These findings mainly come from a population of caregivers with Asian, Caucasian and non-Caucasian American ethnic origins. We are much less confident

(expectations) and behaviours central to familial relationships or relationships within the wider community.			willingness to provide care varied across time.	[few studies] for: Black African and Arab ethnic origins; reported illness (other than dementia); Middle East, Africa, Australia and Oceania, South America.	studies] for: Black African and Arab ethnic origins; reported illness (other than dementia); Middle East, Africa, Australia and Oceania, South America. The theme reflected in the developing countries.		about these findings for: Black African and Arab ethnic origins; reported illness (other than dementia); Middle East, Africa, Australia and Oceania, South America.
Personal characteristics, beliefs and resources: Individual characteristics, beliefs and resources pertaining to both the caregiver and the care recipient which contribute to motivations for assuming the caregiving role and its continuation.	70 [1,2,18,19,25,26,28–30,32–34,5,37,38,40–42,45–49,7,50–55,58,60–62,9,64–67,70,72,73,75–77,10,78–81,83,87–91,11,92,93,95–102,12,13,17]	Very minor concerns regarding methodological limitations that are unlikely to reduce confidence in the review finding. Removal of one article with low methodological quality did not change this theme.	Very minor concerns about coherence across studies that are unlikely to reduce confidence in the review finding. Across and within studies, there are varied and diverse experiences between caregivers that reflect the personal determinants of motivations to provide care.	No or very minor concerns regarding data adequacy related to female caregivers with Asian and Caucasian ethnic origins. Minor or moderate concerns [few studies] for: non-Caucasian American, Black African ethnic origins; reported illness (other than dementia); Australia and Oceania, South America. Serious concerns about adequacy [lack of studies] pertaining to Middle East and Arab ethnicity.	Very minor concerns regarding relevance related to female caregivers with Asian and Caucasian ethnic origins. Minor or moderate concerns [few studies] for: non-Caucasian American, Black African ethnic origins; reported illness (other than dementia); Australia and Oceania, South America. Serious concerns about relevance [lack of studies] pertaining to Middle East and Arab ethnicity. The theme reflected in the other developing countries.	**Moderate Confidence**	These findings mainly come from a population of female caregivers Asian and Caucasian ethnic origins. We are much less confident about these findings for: non-Caucasian American, Black African and Arab ethnicities; reported illness (other than dementia); Australia and Oceania, South America and Middle East.

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A6 Appendix - GRADE-CERQual Qualitative Evidence Profile - Summary of findings and assessment of confidence in analytic themes

Analytic Theme	Studies contributing to finding	Methodological limitations	Coherence	Adequacy	Relevance	CERQual rating	Comments
***Cultural values and beliefs*:** Cultural context of caregiving is foundational for the caring experience with cultural beliefs, norms and socialization, religious beliefs and values as motivating factors for caregivers to provide care, even in the changing cultural contexts (acculturation).	64 [1–64]	Very minor concerns regarding methodological limitations that are unlikely to reduce confidence in the review finding. Removal of two articles with low methodological quality did not change this theme.	No or very minor concerns about coherence across studies that are unlikely to reduce confidence in the review finding.	Very minor concerns regarding data adequacy related to female caregivers who are adult children with Asian ethnicity. Minor or moderate concerns [few studies] for: male caregivers, ethnicity other than Asian, spousal relationship type and reported illness (other than dementia).	No or very minor concerns about relevance related to female caregivers with Asian ethnicity. Moderate concerns [few studies] for: male caregivers, ethnicity other than Asian, reported illness (other than dementia) and continents of South America and Australia and Oceania. The theme reflected in the developing countries as well.	**High Confidence**	These findings come mainly from a caregiving population of female caregivers with mostly Asian ethnic origins. Less confidence should be acknowledged for male caregivers, ethnicity other than Asian and continents of South America and Australia and Oceania.
***Societal norms and perceived expectations*:** The impact of societal structure on caregiving on both personal (individual) and collective (public) levels, evidenced in	65 [1,3,13,15,16,18,19,21,22,24,25,29,4,30–34,36–40,6,41–43,45–47,50,53,55,56,7,57,59,60,62,64–69,8,70–	Very minor concerns regarding methodological limitations that are unlikely to reduce confidence in the review finding. Removal of two articles with low methodological quality did not change this theme.	No or very minor concerns about coherence across studies that are unlikely to reduce confidence in the review finding. Societal norms and perceived expectations varied across cultures	Very minor concerns regarding data adequacy related to female caregivers who are adult children with Asian ethnicity as well as Caucasian and non-Caucasian American ethnicity. Minor or moderate concerns [few studies] for: male	No or very minor concerns about relevance related to female caregivers with Asian ethnicity as well as Caucasian and non-Caucasian American ethnicity. Minor or moderate concerns [few studies] for: male	**High Confidence**	These findings come predominantly from a caregiving population of female caregivers with mainly Asian ethnic origins and/or Caucasian and non-Caucasian American ethnicity. Less

(a) requirements such as roles, norms and expectations specifying what is societally normative in terms of caregiving and (b) formal resources, services, policies (systems).	79,9,80–84,10–12]		(ethnicities) and caregivers.	caregivers; Black African and Arab ethnic origins; spousal relationship type and reported illness (other than dementia).	caregivers; Black African and Arab ethnic origins; reported illness (other than dementia). The theme reflected in the developing countries. Social policy intent almost exclusively considered in Asia and/or carers with Asian ethnic origins and/or developing countries.		confidence should be acknowledged for: male caregivers; carers with Black African and Arab ethnic origins.

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A7 Appendix - Summary of assessment of analytic themes and descriptive subthemes by selected study characteristics

Meta-synthesis part	Analytic theme	Descriptive subtheme	No. of articles contributing to subtheme	No. of articles with low methodological quality (N=4 in total) contributing to subtheme	No. of articles with only men caregivers (N=7 in total) contributing to subtheme	No. of articles with longitudinal study design (N=16 in total) contributing to subtheme	No. of articles selected by caregiver ethnicity contributing to subtheme					No. of articles selected by relationship type contributing to subtheme		No. of articles selected by care recipient's most recurrently reported illnesses contributing to subtheme				No. of articles selected by age above 64 (N=3) contributing to subtheme	No. of articles selected by the continent contributing to subtheme							No. of articles with developing countries (N=20 in total) contributing to subtheme
							With a majority (at least 85%) of Caucasian ethnicity (N=25 in total)	Asian ethnicity (N=36 in total)	non-Caucasian American ethnicity (N=10 in total)	Black African ethnicity (N=6 in total)	Arab ethnicity (N=2 in total)	With a majority (at least 90%) of adult children (N=24 in total)	With majority (at least 90%) of spouses/partners (N=11 in total)	Strokes (N=5 in total)	Cardiac diseases (N=3 in total)	Cancers (N=7 in total)	Dementias (N=36 in total)		Asia (N=23 in total)	Middle East (N=3 in total)	Africa (N=6 in total)	Europe (N=22 in total)	Australia and Oceania (N=4 in total)	North America (N=49 in total)	South America (N=1 in total)	
Cultural and societal motivations for providing informal care *(reported elsewhere)*	*1. Cultural values and beliefs*	*1.1 Cultural-specific norms of providing care*	37 [1–37]	N/A	1 [32]	4 [2,14,18,25]	1 [13]	25 [1,4,19–22,24,25,27–30,5,31,33,34,36,7–10,16–18]	2 [26,38]	2 [3,11]	1 [37]	9 [1,9,12–14,16,22,25,33]	2 [2,24]	2 [7,31]	N/A	2 [4,28]	12 [8,12, 30,37, 13,14, 16,20, 21,25, 27,29]	1 [24]	16 [1,4,32,34,36,39,6,7,14, 16,24, 28,29, 31]	1 [37]	2 [3,11]	2 [8,15]	N/A	18 [2,5,21,22,25–27,30,33,35,9,10,13, 14,17–20]	N/A	7 [3,7,11,24,28,29,31]
		1.2 Socialization	22 [1,2,21,22,37, 38,40–45,6,46,47,7,9,10,13,14,16,20]	N/A	1 [47]	2 [2,14]	3 [13,41,47]	9 [1,7,9,10, 16,20–22,42]	2 [44,46]	1 [43]	1 [37]	9 [1,9,13, 14,16,22,42,43,47]	1 [2]	1 [7]	N/A	1 [40]	8 [13,14,16,20, 21,37, 45,46]	N/A	6 [1,6,7, 14,16, 42]	1 [37]	1 [43]	1 [47]	N/A	14 [2,9,41,44–46,10,13,14,20–22,38,40]	N/A	3 [7,42,43]
		1.3 Spirituality and religion	28 [3,4,39–41,45,48–53,8,54–61,9,12,20,22, 29,34,37]	2 [53,56]	1 [49]	3 [51,55,58]	5 [41,54–56,59]	12 [4,8,58,60,9,20,22,29,34,39,50,57]	N/A	2 [3,51]	2 [37,61]	7 [9,12,22,48,49,55,59]	N/A	N/A	1 [55]	4 [4,40,50,61]	9 [8,12, 20,29, 37,45, 49,54, 60]	N/A	6 [4,29, 34,50, 53,57]	2 [37,61]	2 [3,51]	3 [8,54,58]	N/A	14 [9,18,53,56,59,60,20,22,40,41, 45,48,49,52]	N/A	6 [3,29,39,50, 51,61]
		1.4 Acculturation	9 [3,18,19,22,25,33,43,60,62]	N/A	N/A	2 [18,25]	N/A	7 [18,19,22, 25,33,60,62]	N/A	2 [3,43]	N/A	5 [22,25,33,43,62]	N/A	N/A	N/A	N/A	2 [25,60]	N/A	N/A	N/A	2 [3,43]	N/A	1 [62]	5 [19,22,25, 33,60]	N/A	2 [3,43]
		1.5 Cultural aspects of illness beliefs	5 [5,29,37,63,64]	N/A	N/A	N/A	1 [64]	2 [5,63]	N/A	N/A	1 [37]	N/A	1 [63]	N/A	N/A	N/A	4 [29,37,63,64]	N/A	2 [29,63]	1 [37]	N/A	1 [64]	N/A	1 [5]	N/A	2 [29,63]
	2. Societal norms and perceived expectations	*2.1 Seeking social recognition and conforming to societal pressure*	24 [3,9,34,35,37, 39,40,43,48,50,51,57,11,63, 65–67,12,16,19,24,25,29,31]	N/A	N/A	3 [25,51,67]	2 [65,66]	12 [9,16,57,63,19,24,25,29,31,34, 39,50]	N/A	5 [3,11,43,51,67]	1 [37]	5 [12,16,25,43,48]	2 [24,63]	2 [31,66]	N/A	2 [40,50]	6 [12,16,25,29, 37,63]	1 [24]	10 [16,24,29,31,34,39,50,57,63]	N/A	5 [3,11, 43,51, 67]	2 [65,66]	N/A	6 [9,19,25,35,40,48]	N/A	11 [3,11,67,24, 29,31,39,43, 50,51,63]

			2.2 Gender-specific roles	32 [1,3,30,35,39,42–44,46,47,59,62,4,67–76,10,12,13,16,18,24,29]	2 [56,69]	3 [47,71,76]	2 [18,67]	7 [13,47,59,69,71–73]	9 [1,4,10,16,18,29,30,39,42,62]	5 [44,46,68,75,76]	3 [3,43,67]	N/A	12 [1,12,71,72,13,16,42,43,47,59,62,69]	N/A	N/A	N/A	1 [4]	10 [12,13,16,29,30,46,70,71,73,77]	N/A	6 [1,4,16,29,39,42]	N/A	3 [3,43,67]	3 [47,71,73]	2 [62,70]	13 [10,13,72,74,76,18,30,35,44,46,59,68,69]	1 [75]	7 [3,29,39,42,43,67,75]
			2.3 Social policy intent and assumptions underpinning this	8 [6,7,31,34,35,50,76,78]	N/A	1 [76]	N/A	N/A	4 [7,31,34,50]	1 [76]	N/A	N/A	N/A	N/A	2 [7,31]	N/A	1 [50]	N/A	N/A	5 [6,7,31,34,50]	N/A	N/A	N/A	1 [78]	2 [35,76]	N/A	3 [7,31,50]
			2.4 Perceived limitations to formal support provision and services	13 [7,15,75,77,79,18,33,37,41,43,50,54,60]	N/A	N/A	N/A	3 [41,54,77]	5 [7,18,33,50,60]	2 [43,75]	N/A	1 [37]	3 [33,43,79]	N/A	1 [7]	N/A	1 [50]	3 [37,54,60]	N/A	1 [7,50]	1 [37]	1 [43]	3 [15,54,77]	N/A	5 [18,33,41,60,79]	2 [43,75]	4 [7,43,50,75]
			2.4 Avoiding admission to a care home	29 [7,8,30,33,35,37,38,41,45,62,71,73,10,74,78–84,12,15,18,19,21,22,25]	N/A	2 [71,82]	3 [18,25,83]	4 [41,71,73,82]	12 [7,8,62,84,10,18,19,21,22,25,30,33]	2 [38,80]	N/A	1 [37]	7 [12,22,25,33,62,71,79]	2 [80–82]	2 [7,80]	1 [84]	N/A	10 [8,12,21,25,30,37,45,71,73,82]	1 [82]	1 [7]	2 [37,84]	N/A	6 [8,15,71,73,81,83]	2 [62,78]	16 [10,18,41,45,74,79,80,82,19,21,22,25,30,33,35,38]	N/A	2 [7,84]
Contextual, personal and relational motivations for providing informal care	*1. Contextual aspects of caregiving*	*1.1 Caregiving context*	*1.1.1 Convenience factors*	18 [4,8,52,58,61,69,72,74,85,86,16,22,35,40–42,47,48]	2 [69,85]	1 [47]	1 [58]	4 [41,47,69,72]	8 [4,8,16,22,42,58,85,86]	N/A	N/A	1 [61]	7 [16,22,42,47,48,69,72]	N/A	N/A	1 [85]	3 [4,40,61]	2 [8,16]	N/A	6 [4,16,42,61,85,86]	N/A	N/A	3 [8,47,58]	N/A	8 [22,35,40,41,48,52,69,74]	N/A	4 [42,61,85,86]
			1.1.2 Dependence on the care recipient	4 [15,41,45,59]	N/A	N/A	N/A	2 [41,59]	N/A	N/A	N/A	N/A	1 [59]	N/A	N/A	N/A	N/A	1 [45]	N/A	N/A	N/A	N/A	1 [15]	N/A	3 [41,45,59]	N/A	N/A
			1.1.3 Competing priorities and demands	17 [4,9,47,55,62,67,76,86,87,10,17,19,21–23,34,39]	N/A	2 [47,76]	2 [55,67]	2 [47,55]	11 [4,9,86,10,17,19,21,22,34,39,62]	1 [76]	1 [67]	N/A	5 [9,22,47,55,62]	N/A	N/A	1 [55]	1 [4]	2 [21,87]	N/A	4 [4,34,39,86]	N/A	1 [67]	2 [47,87]	1 [62]	8 [9,10,17,19,21,22,55,76]	N/A	3 [39,67,86]
		1.2 Temporal aspects of caregiving		14 [2,8,15,21,25,55,57,81,88–93]	N/A	N/A	6 [2,25,55,88,92,93]	5 [55,89–92]	4 [8,21,25,57]	N/A	N/A	N/A	2 [25,55]	4 [2,81,92,93]	N/A	1 [55]	N/A	7 [8,21,25,88,90,92,93]	1 [93]	1 [57]	N/A	N/A	7 [8,15,81,89,90,92,93]	1 [88]	5 [2,21,25,55,91]	N/A	N/A

	2. The nature of relationship	*2.1. Reciprocity*	*2.1.1 Retrospective reciprocity*	59 [2,4,19,22–26,28,31–33,7,36,38,39,41,44,45,47–50,8,51–53,56,57,59–63,9,65,66,68–71,73–75,81,12,82,83,85–87,93–97,14,98,16–18]	3 [53,69,85]	6 [32,47,49,71,82,97]	10 [2,14,18,25,51,83,93–95,97]	12 [41,47,94,98,56,59,65,66,69,71,73,82]	22 [4,7,24,25,28,31,33,36,39,57,60,62,8,63,85,9,16–19,22,23]	5 [26,38,44,68,75]	1 [51]	1 [61]	16 [9,12,49,59,62,69,71,94,14,16,22,23,25,33,47,48]	7 [2,24,63,81,82,93,96]	3 [7,31,66]	1 [85]	3 [4,28,61]	18 [8,12,71,73,82,87,93,95–97,14,16,25,45,49,60,63,70]	3 [24,82,93]	14 [4,7,53,57,63,85,14,16,24,28,31,32,36,39]	1 [61]	1 [51]	11 [8,47,98,65,66,71,73,81,83,87,93]	2 [62,70]	30 [2,9,33,38,41,44,45,48,49,52,53,56,14,59,60,68,69,74,82,94–97,17–19,22,23,25,26]	1 [75]	10 [7,24,28,31,39,51,61,63,75,85]
			2.1.2 Expected reciprocity	25 [9,10,43,45,47–49,51,57,59,60,65,11,67,74,87,94,97,13,16,17,30,33,37,38]	N/A	3 [47,49,97]	5 [51,67,94,95,97]	5 [13,47,59,65,94]	7 [9,10,16,17,30,33,57,60]	1 [38]	4 [11,43,51,67]	1 [37]	10 [9,13,16,33,43,47–49,59,94]	N/A	N/A	N/A	N/A	9 [13,16,30,37,45,49,60,87,97]	N/A	2 [16,57]	1 [37]	4 [11,43,51,67]	2 [65,87]	N/A	17 [9,10,59,60,65,74,87,94,97,13,17,30,33,38,45,48,49]	N/A	4 [11,43,51,67]
		2.2 Out of affection		58 [2,7,27,28,31,32,38,39,41,44–46,14,47–49,51–55,57,59,15,60,61,64–66,70–73,75,16,76,79,81–84,86,88–90,20,92–94,98–102,22–24,26]	1 [53]	6 [32,47,49,71,76,82]	10 [2,14,51,55,83,88,92–94,99]	21 [41,47,73,82,89,90,92,94,98,101,102,54,55,59,64–66,71,72]	14 [7,16,57,60,84,86,20,22–24,27,28,31,39]	8 [26,38,44,46,75,76,99,100]	1 [51]	1 [61]	13 [14,22,79,94,99,23,47–49,55,59,71,72]	6 [2,24,81,82,92,93,101]	4 [7,31,66,100]	2 [55,84]	2 [28,61]	20 [14,16,70,71,73,82,88,90,92,93,99,102,20,27,45,46,49,54,60,64]	3 [24,82,93]	11 [7,14,86,16,24,28,31,32,39,53,57]	2 [61,84]	1 [51]	18 [15,47,89,90,92,93,98,101,102,54,64–66,71,73,81,83]	2 [70,88]	2 [70,88]	1 [75]	10 [7,24,28,31,39,51,61,75,84,86]
		2.3 Relationship quality		36 [1,2,45–48,54,63,66,71,72,75,16,76,81,83,85,86,88–92,26,93,96–98,101,103,33–35,40,41,44]	1 [85]	4 [47,71,76,97]	7 [2,83,88,92,93,95,97]	14 [41,47,98,101,103,54,66,71,72,89–92]	7 [1,16,33,34,63,85,86]	4 [26,44,46,75]	N/A	N/A	7 [1,16,33,47,48,71,72]	7 [2,63,81,92,93,96,101]	1 [66]	1 [85]	2 [40,91]	13 [16,45,96,97,103,46,54,63,71,88,90,92,93]	1 [93]	6 [1,16,34,63,85,86]	N/A	N/A	13 [47,54,98,101,103,66,71,81,83,89,90,92,93]	1 [88]	15 [2,26,72,76,91,96,97,33,35,40,41,44–46,48]	1 [75]	4 [63,75,85,86]
		2.4 Family values		30 [3,4,38,39,41,46,47,49,52–54,59,9,60,61,65,68,70,87,98–100,103,10,11,15,20–22,31]	1 [53]	2 [47,49]	1 [99]	7 [41,47,54,59,65,98,103]	8 [4,9,10,20,21,31,39,60]	5 [38,46,68,99,100]	1 [3]	1 [61]	6 [9,22,47,49,59,99]	N/A	2 [31,100]	N/A	2 [4,61]	10 [20,21,46,49,54,60,70,87,99,103]	N/A	5 [4,31,39,53,61]	N/A	2 [3,13]	7 [15,47,54,65,87,98,103]	1 [70]	16 [9,10,53,59,60,68,99,100,20–22,38,41,46,49,52]	N/A	4 [3,11,31,39,61]
		2.5 Obligations to provide care		90 [1,3,15–24,4,25,27,30–37,5,38,40–48,7,49–55,57–	3 [53,69,85]	6 [32,47,49,71,76,97]	14 [14,18,93–95,97,25,51,55,58,67,83,88,92]	21 [13,41,71–73,77,89,91,92,94,101,102,47,1	31 [1,4,19–22,24,25,27,30,31,33,5,34,36,4	8 [38,46,68,75,76,80,95,100]	5 [3,43,51,67,105]	2 [37,61]	19 [1,9,47–49,55,59,62,69,71,94,13,14,16,22	7 [24,80,81,92,93,101,104]	5 [7,31,66,80,100]	3 [55,84,85]	6 [4,40,50,61,91,104]	29 [8,13,45,46,49,54,60,64,70,71,	2 [24,93]	18 [1,4,37,42,50,53,57,61,85,86,7	1 [84]	5 [3,43,51,67,105]	20 [8,15,77,81,83,87,89,92,93,101–103,47,54,	4 [62,70,78,88]	41 [5,9,22,25,27,30,33,35,38,40,41,44,10,45,46,48,49,	1 [75]	14 [3,7,75,84,85,105,24,31,42,43,50,51,61,67]

			59,8,60–62,64–70,9,71–78,80,81,10,83–89,91–93,13,94,95,97,100–105,14]				03,54,55,59,64–66,69]	2,50,57,58,60,62,84,85,7,86,8–10,16–18]				,25,33,42,43]					73,77,14,87,88,92,93,95,97,102,103,105,16,20,21,25,27,30,37]		,14,16,24,31,32,34,36]			58,64–66,71,73]		52,53,55,59,60,68,13,69,72,74,76,80,91,94,95,97,100,14,104,17–21]		
	3. Personal characteristics, beliefs and resources	*3.1 Caregiver's personal characteristics and resources*	14 [15,16,88,89,94,98,23,28,31,41,44,54,62,75]	N/A	N/A	2 [88,94]	5 [41,54,89,94,98]	5 [16,23,28,31,62]	2 [44,75]	N/A	N/A	4 [16,23,62,94]	N/A	1 [31]	N/A	1 [28]	3 [16,54,88]	N/A	3 [16,28,31]	N/A	N/A	4 [15,54,89,98]	2 [62,88]	4 [23,41,44,94]	1 [75]	3 [28,31,75]
		3.2 Caregiving experience and expertise/competence	7 [38,51,60,61,77,87,91]	N/A	N/A	1 [51]	2 [77,91]	1 [60]	1 [38]	1 [51]	1 [61]	N/A	N/A	N/A	N/A	2 [61,91]	3 [60,77,87]	N/A	1 [61]	N/A	1 [51]	2 [77,87]	N/A	4 [38,60,91]	N/A	2 [51,61]
		3.3 Coping responses	55 [1,2,27,28,31,36,38,41,45–48,3,49,50,55,59,60,62–64,66,68,4,71–73,76,79–83,85,7,87,89,91–93,95,97–99,101,15,102,103,105,18–20,22]	1 [85]	6 [47,49,71,76,82,97]	9 [2,18,55,83,92,93,95,97,99]	17 [41,47,89,91,92,98,101–103,55,59,64,66,71–73,82]	16 [1,4,36,50,60,62,63,85,7,18–20,22,27,28,31]	7 [38,46,68,76,80,95,99]	2 [3,105]	N/A	11 [1,22,99,48,49,55,59,62,71,72,79]	8 [2,63,80–82,92,93,101]	4 [7,31,66,80]	2 [55,85]	4 [4,28,50,91]	20 [20,27,82,87,92,93,95,97,99,102,103,105,45,46,49,60,63,64,71,73]	2 [82,93]	9 [1,4,7,28,31,36,50,63,85]	N/A	2 [3,105]	16 [15,47,92,93,98,101–103,64,66,71,73,81,83,87,89]	1 [62]	24 [2,18,48,49,55,59,60,68,72,76,79,80,19,91,95,97,99,20,22,27,38,41,45,46]	N/A	8 [3,7,28,31,50,63,85,105]
		3.4 Finding meaning	26 [4,16,49,51,55,61,63,65,82,83,87,89,22,95,98,100–102,104,23,24,28,31,41,45,47]	N/A	3 [47,49,82]	4 [51,55,83,95]	9 [41,47,55,65,82,89,98,101,102]	7 [4,16,22–24,28,31]	2 [95,100]	1 [51]	1 [61]	6 [16,22,23,47,49,55]	5 [24,63,82,101,104]	2 [31,100]	1 [55]	4 [4,28,61,104]	8 [16,45,49,63,82,87,95,102]	2 [24,82]	7 [4,16,24,28,31,61,63]	N/A	1 [51]	8 [47,65,83,87,89,98,101,102]	N/A	10 [22,23,41,45,49,55,82,95,100,104]	N/A	5 [24,28,51,61,63]
		3.5 Seeing care recipient's illness	14 [3,14,87,89,90,101,20,24,28,30,47,51,61,63]	N/A	1 [47]	1 [14]	5 [20,47,89,90,101]	2 [30,63]	N/A	1 [3]	N/A	2 [14,47]	2 [63,101]	N/A	N/A	N/A	6 [14,20,30,63,87,90]	N/A	2 [14,63]	N/A	[3]	5 [47,87,89,90,101]	N/A	3 [14,20,30]	N/A	3 [3,31,63]

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A8 Appendix - Summary of analytic themes, descriptive subthemes and axial codes with the number of references

Analytic theme		**Descriptive subtheme**	**Axial code in NVivo**	**No. of relevant references**
Contextual aspects of caregiving	Caregiving context	Convenience factors	Geographical proximity	5 [1–5]
			Space and means to provide care	7 [5–11]
			Family structure / Unavailability of other family members	5 [3,12–15]
			Living with a CR before	1 [16]
		Dependence on the care recipient	Imposition of the decision by the CR	3 [7,17,18]
			Socioeconomic dependence on the CR	1 [7]
			Inheritance promises	1 [19]
		Competing priorities and demands	Combining care and work duties	6 [9,20–24]
			Conflicting demands	8 [22,24–30]
			Competing role demands	4 [13,23,31,32]
			Asymmetrical parental and filial priorities	1 [33]
			Perceived burden	2 [3,24]
	Temporal aspects of caregiving		Caregiving journey	8 [18,34–40]
			Fluctuations in caregiving due to CR's changing needs	7 [10,24,27,39,41–43]
The nature of the relationship		Retrospective reciprocity	Retrospective reciprocity	36 [1,3,31,35,37,41,44–49,4,50–59,7,60–65,9,10,12,15,19,20]
			Direct reciprocity (mutual support)	2 [47,66]
			Delayed reciprocity	2 [47,53]
			Virtual reciprocity	5 [4,34,38,50,67]
			Spousal reciprocity	3 [17,68,69]
			Constructed reciprocity	1 [70]
			Waived reciprocity	1 [70]
			Giving back	2 [3,71]
			Paying back	8 [3,25,26,51,61,66,72,73]

		Reciprocal love	1 [74]
		Reciprocating care	1 [17]
		Repaying family	1 [21]
		Repaying the debt to community	1 [75]
		Returning the love	1 [76]
		Showing gratitude	1 [13]
		Debt of heart	2 [8,51]
		The debt	3 [11,33,60]
		Justice concerns	2[35,77]
		'Paying back' is not enough to provide care	2 [28,47]
	Expected reciprocity	Demonstration effect	17 [1,3,37,48,51,66,78–80,15,17,19,23,25,28,29,33]
		Generalized reciprocity	1 [70]
		Preparatory reciprocity	4 [4,47,81,82]
		Giving the caregiving example to community	1 [75]
		To resist the social pressure	3 [46,47,67]
	Out of affection	Love and emotional attachment	36 [1,2,34–36,38,47–50,57,59,3,60–62,65,67,68,71,72,75,77,7,83–88,8,11,17–19,32]
		Showing love and responsibility	2 [13,73]
		Autonomous choice - wanting to care	7 [17,18,38,40,61,62,77]
		Compassionate feelings	2 [31,89]
		Devotion to care / Caring from the heart	9 [21,30,51,56,61,71,73,83,90]
		Determination to care	10 [24,36,39,42,62,65,73,74,84,91]
		Affection	10 [3,15,31,37,46,54,64,90,92,93]
	Relationship quality	Pre-morbid relationship quality	15 [1,2,40,42,61,69,70,3,5,14,15,17,22,35,38]
		Bond established between the CG and CR	5 [39,56,66,72,94]
		Quality of familial relationships	1 [30]

		Maintaining feelings of couplehood	2 [36,61]
		Strengthening the relationship	7 [43,57,68,71,77,91,95]
		Being together until the end	1 [91]
		Role reversal	3 [1,3,32]
		CR's attitude	10 [15,17,34,40,43,53,61,71,72]
		CR's level of dependence	4 [7,42,61,95]
		CR's level of communication	6 [7,38,42,58,61,95]
		Losing CR’s identity	5 [17,36,42,87,88]
	Family values	Familism	14 [3,7,86,87,89,95,18,19,23,27,46,48,51,67]
		Blood relations	2 [49,96]
		Family ties	3 [13,21,83]
		Kin-keepers	9 [8,9,13,25,33,48,51,62,65,67]
		Treating a CR respectfully	2 [48,88]
		Caregiving as an indication of respect	4 [11,44,62,82]
		Protective instincts	1 [71]
	Obligations to provide care	Obligation to provide care	20 [4,7,46–48,51,55,59,70,86,90,92,8,11,15,37–40,43]
		Duty to provide care	7 [17,18,49,56,74,95,97]
		Caregiving responsibility	6 [1,36,37,90,91,98]
		Obligation without a choice	19 [1,2,24,38,49,61,65,72,76,80,99,3,4,9,12,14,16–18]
		Obligation and guilt	12 [1,17,68,93,19,25,36,40,47,49,61,65]
		Moral obligation and considerations	10 [3,22,40,44–46,49,64,65,87]
		Filial piety	21 [9,13,33,37,41,65,66,74,76,89,92,94,16,100,22,23,26–28,30,31]

		Filial obligation	15 [1,3,33,45,51,88,90,5,6,8–11,19,20]
		Filial responsibility	8 [13,20,24,51,62,77,81,101]
		Spousal obligation	24 [10,17,50,53,54,59,61,65,67,68,72,74,18,84,88,102,27,28,32,34,37,38,49]
		Obligation and maintaining a marital relationship	1 [78]
		Relationship obligation	2 [25,38]
		Family's obligation to care	6 [5,17,29,79,81,96]
		Collective (community) responsibility	3 [75,96,103]
Personal characteristics, beliefs and resources	Caregiver's personal characteristics and resources	Belief in natural affinity for caregiving	3 [31,39,77]
		Caring nature	3 [15,18,72]
		Dispositional optimism (Feelings of hope)	5 [7,65,71,73,88]
		Physical ability to deal with caregiving	2 [20,40]
		Having one's own children	1 [47]
		Age	1 [20]
	Coping	Being grateful for the current situation (positive reframing)	1 [36]
		Distracting oneself through focusing on caregiving personal care tasks	1 [56]
		Viewing care recipient's anticipated death as a rescuer	1 [68]
		Using humour (as a defensive strategy)	3 [43,61,93]
		Preparing for caregiving (Planning)	1 [36]
		Attending one’s own needs	1 [71]

		Engaging in religious practices as means of emotional and social support	17 [13,32,87,89,92–94,96,102,35,38,45,48,55,58,74,83]
		Using available family support	21 [1,2,40,51,53,56,59,65,74,76,83,85,3,87,92,7,13,18,20,26,32,38]
		Sharing caregiving duties with family	6 [2,17,67,83,92,95]
		Seeking formal social support	7 [24,38,87,92,95,101,102]
		Seeking social isolation	6 [9,25,43,56,65,73]
		Attending support groups	3 [38,84,92]
		Seeking connectedness with other caregivers	1 [65]
		Using respite care support	4 [60,87,93,95]
		Using professional help	3 [43,70,76]
		Using formal home care services	4 [56,83,85,91]
		Having 'me' time	2 [36,102]
		Taking control and accepting the situation	11 [18,19,103,25,34,36,44,65,71,93,95]
	Caregiving experience and expertise/competence	Having taken care in the past	2 [25,48]
		Caregiving competence and skills	4 [8,43,67,98]
		Personal experience with illness and death	1 [75]
		Hoping to become a professional carer	1 [75]
	Finding meaning	Meaning making	10 [3,24,31,51,58,60,65,71,91,97]
		Authentic living	2 [25,91]
		Past meanings	2 [25,86]
		Altruistic satisfaction	2 [17,75]
		Identification with the role	2 [8,9]

		Growth	3 [15,31,71]
		Purpose for living	9 [7,13,40,46,54,55,61,73,91]
		A reason to reconnect in a relationship	3 [3,65,93]
	Seeing care recipient's illness	Perceiving illness	6 [40,58,64,79,89,96]
		Perception of the severity of CR's illness	2 [42,91]
		CR's meaningless illness	2 [3,25]

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A9 Appendix - Summary of analytic themes, descriptive subthemes and axial codes with the number of references

Analytic theme	Descriptive subtheme	Axial code in NVivo	No. of relevant references
Cultural values and beliefs	Cultural-specific norms of providing care	Cultural-specific norms	24 [1–24]
		Cultural values	20 [4,6,8,9,12,20,24–37]
	Cultural socialisation	Caregiving cultural socialisation (Preparation for the role)	18 [1,2,6,7,9,10,13,14,16,27,36–43]
		Role modelling by the CG's family members	3 [24,27,44]
		Upbringing	2 [45,46]
	Acculturation	Caregiving acculturation	4 [20,34,42,47]
		Adjusting to new culture	4 [27,28,33,48]
		Disconnection between western and traditional medicine	2 [3,33]
	Spirituality and religion	Religious beliefs and values	15 [3,4,12,24,26,36,38,49–56]
		God's will	5 [27,44,55,57,58]
		Karma	5 [8,9,21,36,59]
		Religious duty	8 [3,12,40,47,50,60–62]
	Cultural aspects of illness beliefs	Stigmatization because of an illness	2 [26,63]
		Social perceptions of CR’s illness	3 [5,24,64]
Societal norms and perceived expectations	Seeking social recognition and conforming to societal pressure	Appreciation shown by others	4 [12,22,50,65]
		Need for recognition	4 [9,42,55,63]
		Pressure from public opinion and Caregiving socially sanctioned	17 [3,11,12,16,18,21,24–26,28,34,38,49,54,59,66,67]

	Gender-specific roles	Gender-specific norms	26 [1,3,4,10,12,13,16,18,22,26,31,33,41–43,45,46,48,66,68–74]
		Female duty	5 [13,49,61,69,75]
		Women are better caregivers	3 [10,45,69]
		Men are stronger	1 [45]
		Men unrecognized as carers	1 [76]
	Social policy intent and assumptions underpinning this	Assuming that couples are willing to care	1 [77]
		Valuable social and economic resource	1 [77]
		Implicit lawful obligation to provide care	1 [6]
		Legislation to encourage filial piety	1 [6]
		Benefits	1 [22]
	Perceived limitations to formal support provision and services	Dissatisfaction with formal services	2 [15,78]
		Lack of financial conditions to hire a professional CG	1 [75]
		Lack of knowledge and support	2 [7,56]
		Lack of places in institutions	2 [40,42]
		Lack of respite care services	2 [24,79]
		Pressure from professionals	2 [40,54]
		Language barriers	3 [20,33,47]
	Avoiding admission to a care home	Anti-institutional feelings	21 [7,8,12,20,27,28,31,34,37,39,40,44,48,71,73,74,79–83]
		Independent care as a cultural value	9 [10,12,15,20,24,34,39,77,84]
		Fear of the quality of formal care	4 [7,15,22,40]
		Needing to maintain privacy (of caring)	1 [33]

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A10 Appendix - Reference list of included studies. The reference list of studies included in the meta-synthesis of personal and relational motivations for providing informal care, altogether with other theoretical/empirical papers mentioned in the Findings section.[1]

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[1] The exclusive reference list of 84 studies included in the meta-synthesis of cultural and societal motivations for providing informal care can be found in A5 and A8 Appendices

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A11 Appendix - Reference list of included studies. The reference list of studies included in the meta-synthesis of cultural and societal motivations for providing informal care, altogether with other theoretical/empirical papers mentioned in the Findings section.[2]

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A12 Appendix – Descriptive map. A systematic map with characteristics of included studies

No	**Authors (date)**	**Country setting**	**Aims**	**Caregiver Numbers**	**Carer mean age in years (range)**	**Carer gender (% female)**	**Carer ethnicity or nationality (%)**	**Relationship to care recipient (if reported - %)**	**Care recipient's diagnosis**	**Mean length caring in years (range)**	**Other care experience**	**Employment status (% employed)**	**Sampling**	**Data collection**	**Qualitative methodology** **Theoretical background** **Data analysis**	**Data coded to analytic themes**	**Methodological quality summary (The second dimension)** - Quality score (max 20) for the 'Soundness of the study' - Appropriateness of study design and analysis plus Relevance of the study focus
1	Albinsson and Strang (2003)	Sweden	To explore issues of freedom, responsibility, existential isolation, death, meaning and coping.	20	59 (48–80)	12 (60%)	NR	Daughter = 9 (45%) Son = 3 (15%) Husband = 3 (15%) Wife = 1 (5%) Brother = 1 (5%) Niece = 1 (5%) Brother in-law = 1 (5%) Daughter in-law = 1 (5%)	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Qualitative hermeneutic methodology Existential perspective Hermeneutic analysis	The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	19 High
2	Alonso et al. (2018)	USA	To examine caregiver experiences in the context of the caregiver empowerment model.	23	43 (NR)	18 (78%)	Caucasian White = 20 (87%) Asian = 2 (9%) African American/Black = 1 (3%)	Adult children = 23 (100%)	(End-stage) Heart failure	4.8 years (NR)	Caring for children, grandchildren or an ill sibling or spouse = 16 (69%)	19 (83%)	Purposive	Longitudinal, face-to-face or telephone and one-to-one semi-structured interviews	NR Caregiver empowerment model; caregiver stress and coping models Thematic analysis	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	20 High
3	Anngela-Cole and Busch (2011)	Hawaii (USA)	To investigate stress, anticipatory mourning, and cultural practices among caregivers from different ethnocultural groups.	56	57.9 (NR)	51 (91%)	Japanese = 17 (30%) Caucasian = 14 (25%) Chinese = 13 (23%) Hawaiian = 12 (21%)	NR	Cancer	NR	NR	NR	Purposive	Cross-sectional, semi-structured interviews, 8 focus groups (not organised by ethnicity)	Qualitative phenomenological methodology Caregivers stressors; Anticipatory grief Thematic analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	16 Moderate
4	de Leon Arabit (2005)	California (USA)	To explore the caregiving sentiments and coping strategies of Latino caregivers.	5	NR (57-85)	5 (100%)	Latino = 5 (100%)	Spouse = 5 (100%)	Stroke	NR (2-9 years)	NR	0 (0%)	Purposive	Cross-sectional, face-to-face or telephone and one-to-one semi-structured interviews	Grounded theory NR Constant comparative method	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	18 High
5	Aronson (1992)	Canada	To explore women's experiences of feeling responsible for elderly relatives.	28	NR (35-80)	28 (100%)	'Mainly white Canadian-born women'	Adult daughter = 28 (100%)	Various 'chronic health conditions'	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one unstructured interviews	NR Feminist perspective; Analysis of gender relations NR	Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	12 Low
6	Arpanantikul (2018)	Thailand	To identify Thai women's perspectives on home-based care for family members with chronic illness.	15	48 (35-55)	15 (100%)	Thai = 15 (100%)	Adult children, spouse, siblings.	NR ('Chronic illness')	9.13 years (5-30)	NR	10 (67%)	Purposive	Cross-sectional, semi-structured interviews	Interpretive phenomenology approach NR Thematic analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	19 High
7	Asahara et al. (2002)	Japan	To understand the motivation of family caregivers to continue caring	27	NR	NR	Japanese = 27 (100%)	NR	NR ('Impaired elderly')	NR	NR	NR	Purposive	Cross-sectional, NR	Ethnographic methodology NR	N/A	10 Low

			for the impaired elderly.												Ethnographic analysis + domain and taxonomic analyses		
8	Bäckström and Sundin (2010)	Sweden	To illuminate meanings of being a close relative of a stroke survivor.	10	56 (40–64)	8 (80%)	Swedish = 10 (100%)	Spouses, mother, common law.	Stroke	NR	NR	9 (90%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	The phenomenological-hermeneutic approach NR Analysis - naive reading, structural analysis, comprehensive understanding (Lindseth and Norberg 2004)	Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	19 High
9	Almeida et al. (2018)	Brazil	To understand the reasons of caregiving.	12	NR (60-77)	12 (100%)	'Brown' = 8 (67%) 'Black' = 2 (17%) 'White' = 2 (17%)	'Mostly wives' (the others were daughters and sisters).	NR (Various)	9 months-35 years	NR	1 (8%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR Concepts of extrinsic and intrinsic motivations thematic categorical analysis	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High
10	Bashir (2014)	UK	To examine family obligations, types of support and remittances provided in a sample of Pakistani-origin individuals.	8	NR	4 (50%)	(British) Pakistani = 8 (100%)	Brother, sister, adult child.	NR ('disability')	NR	NR	NR	Purposive	Longitudinal, face-to-face semi-structured interviews	Qualitative case studies NR NR	Cultural values and beliefs The nature of relationship Contextual aspects of caregiving	16 Moderate
11	Boeije et al. (2003)	Netherlands, Belgium	To examine caregiving commitment when providing total care to spouses with Multiple Sclerosis (MS).	17	58 (39-77)	7 (41%)	NR	Spouse = 17 (100%)	Multiple Sclerosis (MS)	NR	NR	4 (24%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR NR A constant comparative analysis including fragmenting and connecting (Dey, 1993)	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	19 High
12	Browne Sehy (1998)	USA	To explore caregivers' perceptions of the benefits and sacrifices of caregiving, the nature of moral conflict, and justice and care reasoning in making difficult decisions.	10	71 (61-83)	10 (100%)	Caucasians = 6 (60%) Hispanics = 2 (20%) Asians =2 (20%) (1 Japanese American and 1 Filipino)	Spouse/partner = 10 (100%)	Various - congestive heart failure, diabetes mellitus with kidney failure, Alzheimer's disease, bipolar affective disease, undiagnosed motor impairment, stroke	6 years (NR)	NR	1 (10%)	Purposive	Longitudinal, face-to-face and one-to-one semi-structured interviews	Qualitative descriptive design Feminist perspective, Conceptual framework of moral decision making An interpretive reading guide (Brown et al., 1988) - top-down approach	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	19 High
13	Bryant and Lim (2013)	Australia	To explore the value of filial piety in informal caregivers' experiences.	4	NR (41-50)	1 (25%)	Chinese origin (first generation immigrants) = 4 (100%)	Adult child = 3 (75%) Son-in-law = 1 (25%)	NR	NR (at least 1 year)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR Concepts of individualism and collectivism, Concept of filial piety	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	19 High

															Interpretative approach with inductive analysis (Patton, 2002)		
14	Cahill (1999)	Australia	To explore the reasons behind female caregiving roles and the extent to which a choice is available to them.	39	64 (35-85)	39 (100%)	NR	Wife =24 (62%) Daughter =12 (31%) Daughter-in-law =3 (8%)	Dementia	3.5 years (NR)	‘several had prior experience as principal carers’	0 (0%)	Purposive	Cross-sectional, semi-structured interviews	Qualitative descriptive exploratory design Opie’s typology of caregiving motivations Qualitative analysis (Miles & Huberman, 1994)	Societal norms and perceived expectations The nature of relationship	16 Moderate
15	Cash et al. (2013)	Australia	To explore choice for informal caregivers in contemporary Australian social policy.	0 (3 documents)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Purposive	Key documents underpinning Australian social policy in informal caregiving	Discourse analysis approach Social inequality and power imbalance theories; Concepts of individualism and familialism Critical discourse analysis (CDA)	Societal norms and perceived expectations The nature of relationship	17 Moderate
16	Chao and Roth (2000)	Taiwan	To explore the experiences of Taiwanese female caregivers providing care for their parents-in-law.	31	23+ (NR)	31 (100%)	Taiwanese = 31 (100%)	Daughter-in-law = 31 (100%)	Total paralysis/ hemiplegia/ semiplegia	NR (<1 years-21 years)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Grounded Theory NR Constant comparative method	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	18 High
17	Clark and Huttlinger (1998)	Texas (USA)	To explore caregiving experiences and cultural concepts of care among Mexican American families.	8	NR (32-67)	8 (100%)	Mexican-American = 8 (100%)	Adult child = 5 (63%) Grandchild = 1 (13%) Spouse = 2 (25%)	NR	NR (6-12 years)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR Concept of ‘la familia’ (Becera, 1983) NR (Thematic analysis)	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	18 High
18	Donorfio and Kellett (2006)	USA	To explore filial expectations and motivations between caregiving daughters and frail mothers.	11	58 (NR)	11 (100%)	White = 10 (91%) African American = 1 (9%)	Adult daughter = 11 (100%)	NR (‘Frailty’)	6.45 years (1-17 years)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Grounded theory Social constructivist paradigm Grounded Theory Analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	18 High
19	Donovan and Williams (2015)	Canada	To explore how Vietnamese family caregivers experience caregiving for seriously ill family members.	18	NR (16-80)	18 (100%)	Vietnamese-Canadian = 18 (100%)	Spouse = 8 (44%) Daughter = 9 (50%) Daughter-in-law = 1 (6%)	NR	NR (5 months – 5+ years)	NR	NR	Purposive	Longitudinal, one-to-one semi-structured interviews	Case study design PHP model (Donovan et al., 2010) Values and emotions coding (Saldana, 2009)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High
20	Dumit et al. (2015)	Lebanon	To describe the cultural context of cardiac caregiving in Lebanon.	13	46.5 (33-82)	10 (77%)	Lebanese = 13 (100%)	Husband = 2 (15%) Son = 1 (8%) Wife = 6 (46%) Daughter = 4 (31%)	Cardiac disease	NR	NR	Female: 4 (31%) Male: 2 (15%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Qualitative descriptive approach NR Qualitative descriptive analysis	Societal norms and perceived expectations The nature of relationship	18 High
21	Dunér (2010)	Sweden	To describe and analyse the motives,	16	NR (45-87)	11 (69%)	Swedish = 16 (100%)	Adult child = 9 (56%)	NR	NR	NR	9 (56%)	Purposive	Cross-sectional semi-structured interviews	Qualitative lifeworld approach	Societal norms and perceived expectations The nature of relationship	17 Moderate

			experiences and coping strategies of next of kin providing informal care.					Spouse = 5 (31%) Niece = 1 (6%) Neighbour = 1 (6%)							Typology of motives by Kohli & Künemund (2003) Thematic analysis	Personal characteristics, beliefs and resources	
22	Erickson (2002)	North Dakota (USA)	To explore motivations, roles, relationships, personality changes, coping strategies and religiosity in informal caregiving.	30 (15 caregiving couples)	NR (54-71)	15 (50%)	NR	Adult child = 15 (50%) Adult child-in-law = 15 (50%)	NR	7 years (2 months - 29 years)	NR	5 unemployed, 1 retired	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Phenomenological approach NR Phenomenological analysis combined with the Heideggerian approach of hermeneutics	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	17 Moderate
23	Foster (2012)	UK	To explore how couples (people with mild dementia and their spouses) describe their experience of dementia and how they try to cope with it.	12	NR (52–84)	8 (67%)	White British = 12 (100%)	Spouse = 12 (100%)	Dementia	NR (9 months-74 months)	NR	NR	Purposive	Longitudinal, face-to-face and one-to-one semi-structured interviews	Phenomenological approach The concept of anticipatory grief, equity theory, model for coping in people with dementia, theory of normalisation, Awareness Context Theory (ACT) Interpretative Phenomenological Analysis (IPA)	The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	20 High
24	Funk (2012)	Canada	To examine whether, how and in what ways adult children interpret and apply the concept of delayed reciprocity in filial relationships.	28	51 (40-64)	16 (57%)	British Caucasian = 27 (96%) Mexico = 1 (4%)	Adult child = 28 (100%)	NR	NR	11 (39%) - ‘helping’ professions within health and/or social services	25 (89%)	Purposive	Longitudinal, one-to-one semi-structured interviews	Qualitative descriptive design Delayed reciprocity, social exchange and equity theories Thematic analysis	The nature of relationship Personal characteristics, beliefs and resources	17 Moderate
25	Gerdner et al. (2007)	Arkansas Delta (USA)	To describe the experience of African American adults providing in-home care for a family member with chronic confusion living in the Arkansas Delta.	15	57 (44-84)	11 (73%)	African American = 15 (100%)	Daughter = 11 (73%) Son = 3 (20%) Husband = 1 (7%)	Chronic confusion (e.g., dementia)	5.25 (3-10)	NR	NR	Purposive	(Longitudinal), face-to-face semi-structured interviews	Ethnographic approach NR Ethnographic analysis by Kirk and Miller (1986)	The nature of relationship Personal characteristics, beliefs and resources	18 High
26	Globerman (1996)	Canada	To explore motivations to care of caregiving daughters- and sons-in-law.	16	NR (40-61	10 (62%)	Canadian = 16 (100%)	Daughter-in-law = 10 (62%) Son-in-law = 6 (38%)	Alzheimer's Disease	NR	NR	15 (94%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Qualitative interpretive approach NR McCracken's long interview method (1988)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship	18 High
27	Guberman et al. (1992)	Canada	To look at the individual's personal motives for assuming primary caregiving responsibilities and examine the elements that	40	NR (30-80)	40 (100%)	Francophone Quebecois = 40 (100%)	Parent (caring for an adult mentally ill child); children (caring for parent(s)).	NR (frail elderly and mental illness)	NR (<1 to >21 years)	NR	16 (40%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR NR NC (In-depth personal interview as the method of analysis similar to	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	15 Moderate

			come into play in this decision.												ethnographic analysis)		
28	Gurayah (2015)	South Africa	To explore the phenomenon of caregiving for people with dementia in a rural context in South Africa.	5	NR (46–68)	4 (80%)	African = 5 (100%)	Daughter = 3 (60%) Son = 1 (20%) Wife = 1 20%)	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Phenomenological approach NR Thematic analysis	The nature of relationship Personal characteristics, beliefs and resources	16 Moderate
29	Han et al. (2008)	USA	To explore the caregiving experiences of Korean Americans in a cultural context.	24	NR (40 – 80)	20 (83%)	Korean American (all first-generation immigrants) = 24 (100%)	Non-relative = 7 (29%) Mother = 5 (21%) Parents = 4 (17%) Wife = 3 (13%) mother-in-law = 3 (13%) Father-in-law = 1 (4%) Husband = 1 (4%)	Various - diabetes, stroke, dementia, hypertension, arthritis, frailty.	NR (1-20 years)	NR	NR	NR	Cross-sectional, face-to-face, semi-structured focus groups	NR Concept of filial piety Thematic analysis/Qualitative content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	18 High
30	Hanyok et al. (2009)	USA	To examine the experiences and perspectives of caregivers of homebound elderly patients.	22	59.3 (NR)	14 (64%)	Caucasian = 19 (86%) African American = 3 (14%)	Wife = 1 (5%) Son = 4 (18%) Daughter = 4 (18%) Grandchild = 2 (9%) Daughter-in-law = 1 (5%) Grandson-in-law = 1 (5%) Non-related = 9 (41%)	NR (‘Frailty’)	NR	NR	NR	Purposive	Cross-sectional, semi-structured interviews	Ethnographic approach NR Editing style analysis	Cultural values and beliefs The nature of relationship	13 Low
31	Harris (1998)	USA	To understand sons' caregiving experiences.	30	50 (32-71)	0 (0%)	White = 25 (83%) Black (African American) = 5 (17%)	Son = 30 (100%)	Dementia	3.5 years (0.5–11)	NR	1 unemployed	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR NR Content analysis	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources	18 High
32	Harris and Long (1999)	USA & Japan	To explore experiences of men in a caregiving role and the effects of culture on these experiences.	45 (USA – 30; Japan – 15)	Japanese sons: 56 (38-68); American sons: 50 (32-71); Japanese husbands: 75 (60—85); American husbands: 72 (41-91)	0 (0%)	American = 30 (67%) Japanese = 15 (33%)	Japan: husband = 10 (22%) Son = 5 (11%) USA: husband = 15 (33%) son = 15 (33%)	Dementia (USA); dementia, severe impairment, stroke (Japan)	Japanese sons: 5 years (NR); American sons: 3.5 (NR); Japanese husband: 4.5 (NR); American husbands: 5 (NR)	NR	2 unemployed; 11 retired	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR NR NC (‘Cross-cultural analysis’)	Cultural values and beliefs The nature of relationship	16 Moderate
33	Hinton et al. (2008)	USA	To explore the role of religion and spirituality in dementia caregiving among Vietnamese refugee families.	9	NR (29-78)	6 (67%)	Vietnamese (first generation of immigrants) = 9 (100%)	Spouse = 3 (33%) Parent = 5 (56%) Niece = 1 (11%)	Dementia	NR	NR	NR	Purposive	Cross-sectional, semi-structured interviews	NR Concepts of religiosity Thematic coding combined with a deductive coding	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources	17 Moderate
34	Ho et al. (2003)	Canada	To explore Chinese-Canadian caregivers’ feelings about their experiences	12	54 (30–80)	12 (100%)	Chinese-Canadian = 12 (100%)	Wife = 2 (17%) Daughter = 8 (50%) Daughter-in-law = 2 (17%)	Alzheimer’s disease	4 years (<1 to 7 years)	NR	4 (33%)	Purposive	Cross-sectional, face-to-face semi-structured interviews	NR Caregiver stress and coping models, cultural perspective	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship	19 High

			of providing care for relatives with Alzheimer’s disease.												Thematic analysis	Contextual aspects of caregiving	
35	Holroyd (2001)	China (Hong Kong)	To investigate motivations to care for parents in a sample of Chinese caregiving daughters.	20	NR (18 -65)	20 (100%)	Chinese-Cantonese = 20 (100%)	Daughter = 20 (100%)	Various - Hypertension, diabetes, cancer, heart disease and stroke (leading to impaired mobility), incontinence, and inability to feed, wash and dress oneself.	NR (4-30 years)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one interviews	Ethnographic approach Anthropological paradigm, cultural perspective An interpretative narrative analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	17 Moderate
36	Holroyd (2005)	China	To explore caregiving experiences and the impact of culture on these in a sample of elderly wives providing care to their husbands.	20	NR (65-91)	20 (100%)	Chinese = 20 (100%)	Spouse = 20 (100%)	Various - Stroke, cataracts, hip problems, diabetes, paralysis, hypertension, cancer.	NR (2-30 years)	NR	‘generally not employed’	Purposive	Cross-sectional, face-to-face and one-to-one unstructured interviews	Ethnographic approach Anthropological paradigm Constant comparative method (Strauss & Corbin, 1990)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High
37	Holroyd (2003)	China (Beijing)	To explore family obligations in the care of the elderly with chronic illnesses that necessitate almost complete dependency.	10	NR (42-68)	5 (50%)	Chinese = 10 (100%)	Wives, daughters, and husbands, sons.	Heart disease and diabetes.	NR (1-40 years)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one interviews	Ethnographic approach Cultural perspective NR	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	13 Low
38	Hsu and Shyu (2003)	Taiwan	To explore social exchanges and motivations in family caregiving for Chinese caregivers in Taiwan.	12	NR	8 (67%)	Taiwanese = 12 (100%)	Wife = 3 (25%) Husband = 2 (17%) Daughter = 3 (25%) Son = 2 (17%) Daughter-in-law = 2 (17%)	NR	NR (1-7 years, except for 1 participant, who had provided care for more than 10 years)	NR	NR	Purposive	Cross-sectional, one-to-one semi-structured interviews	NR Social Exchange, Indebtedness, Inequity Theory Inductive analysis and constant comparison	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	18 High
39	Hsueh et al. (2008)	USA	To explored the phenomenon of acculturation in parental care among U.S. Chinese caregivers.	21	47.5 (NR)	18 (86%)	Chinese = 21 (100%)	Daughter = 16 Daughter-in-law = 2 Son = 3	NR	NR	NR	Most employed.	Purposive	Cross-sectional, face-to-face semi-structured focus groups (2) and face-to-face, one-to-one semi-structured interviews (14)	NR NR NC (Thematic analysis)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship	19 High
40	Jones et al. (2003)	USA	To explore caregiving commitment and experience of filial caregiving in two groups of Asian American immigrant women.	41	NR (38-68)	41 (100%)	Chinese American = 22 (54%) Filipino American = 19 (46%)	Daughter = 30 (73%) Daughter-in-law = 7 (17%) Combined (providing care for both parents and parents-in-law) = 4 (10%)	NR	NR	NR	1 unemployed	Purposive	Cross-sectional, face-to-face, one-to-one semi-structured interviews	Grounded theory NR Grounded theory analysis	The nature of relationship Personal characteristics, beliefs and resources	19 High
41	Jones et al. (2002)	USA	To describe the nature and process of caring for elderly parents by Chinese and Filipino	41	NR (38-68)	41 (100%)	Chinese American = 22 (54%) Filipino American = 19 (46%)	Daughter = 30 (73%) Daughter-in-law = 7 (17%) Combined (providing care for both parents	NR	NR (1-40 years)	NR	1 unemployed	Purposive	Cross-sectional, face-to-face, one-to-one semi-structured interviews	Grounded theory NR Grounded theory analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High

			American women caregivers.					and parents-in-law) = 4 (10%)								Contextual aspects of caregiving	
42	Kao and Stuifbergen (1999)	Taiwan	To explore the experiences of the decision of institutionalizing an elder in Taiwan by family members.	9	47.67 (NR)	6 (67%)	Taiwanese = 9 (100%)	Adult child = 6 (67%) Spouse = 3 (33%)	Stroke = 5 (56%) Dementia = 2 (22%) Arthritis = 1 (11%) Spinal cord injury = 1 (11%)	NR	NR	NR	Purposive	Cross-sectional, face-to-face, one-to-one semi-structured interviews	NR NR Content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	17 Moderate
43	Kellett (1999)	Australia	To explore family carers' experience when continuing to care within a nursing home context (before, during, and after the admission of an older relative into a nursing home).	14	NR	NR	NR	NR (Various)	NR	NR	NR	NR	Purposive	Longitudinal, face-to-face and one-to-one unstructured interviews	Hermeneutic phenomenology NR Hermeneutic analysis	N/A	13 Low
44	Kietzman et al. (2013)	USA	To examine transitions into caregiver roles, perception of choice and stated reasons for providing care.	42	52.2 (NR)	31 (74%)	White = 18 (43%) Latino = 11 (26%) African American = 8 (19%) Asian/ Pacific Islander = 5 (12%)	Child = 19 (45.2%) Other relative = 10 (23.7%) Friend/acquaintance = 8 (19.1%) Parent = 3 (7.1%) Spouse/partner = 2 (4.8%)	NR	NR	NR	22 (52%)	Purposive	Cross-sectional, telephone, one-to-one semi-structured interviews	Constructivist grounded theory approach Self-determination theory, motivational models Grounded theory analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	18 High
45	Kim and Theis (2000)	USA	To describe the caregiving role in the Korean American family.	30	35+ (NR)	30 (100%)	Korean American = 30 (100%)	Wife = 25 (83%) daughter = 4 (13%) daughter-in-law = 1 (4%)	NR ('disabled or chronically ill elderly')	Most 1-4 years (22); range 0+	NR	Most unemployed (19)	Purposive	Cross-sectional, face-to-face, semi-structured interviews	Descriptive qualitative Caregiver stress and coping models NC (Thematic/content analysis)	Cultural values and beliefs The nature of relationship Contextual aspects of caregiving	15 Moderate
46	Kim (2009)	USA	To understand dementia caregiving and postcaregiving experience from the Korean-American family caregiver perspective.	8	67 (48–84)	7 (88%)	Korean American = 8 (100%)	Wife = 3 (38%) Husband = 1 (13%) Daughter = 3 (38%) Daughter-in-law = 1 (13%)	Dementia	6 years (2-10 years)	NR	3 (38%)	Purposive	Cross-sectional, face-to-face, semi-structured interviews	Transcendental phenomenology Cultural perspective, meaning-making in caregiving Analysis according to the procedure of Moustakas' (1994)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High
47	Knight et al. (2016)	KwaZulu-Natal (South Africa)	To explore the motivations for the provision of care and support by kin in South Africa.	10 households ('rural household' was the unit of analysis)	NR ('relatively old')	NR ('mostly women')	African = 10 (100%)	NR	AIDS	NR	NR	NR	Purposive	Longitudinal, face-to-face and joint semi-structured interviews	NR Theoretical models of kinship, family obligation, resilience and social capital NR	Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	16 Moderate
48	Kodwo-Nyameazea and Nguyen (2008)	USA/Ghana (Africa)	To explored caregiving experiences among Ghanaian-Akan migrants providing care to their relatives in Ghana.	5	31 (22-42)	3 (60%)	Ghanaian-Akan (African)= 5 (100%)	Adult child = 5 (100%)	NR	NR	NR	5 (100%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Grounded theory Cultural perspective Constructivist grounded theory analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship	18 High

49	Kong et al. (2010)	USA	To describe Korean immigrant caregivers' experiences of their relative nursing home placement in USA.	10	54 (40-70)	10 (100%)	Korean = 10 (100%)	Daughter-in-law = 5 (50%) Daughter = 4 (40%) Wife = 1 (10%)	Dementia	NR	NR	6 (60%)	Purposive	Longitudinal, face-to-face and one-to-one semi-structured interviews	Descriptive qualitative Cultural perspective Qualitative content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	19 High
50	Kristanti et al. (2019)	Indonesia	To explore experiences of family cancer caregivers in Indonesia.	24	43 (NR)	16 (67%)	Indonesian = 24 (100%)	Husband = 6 (25%) Daughter = 11 (46%) Wife = 2 (8%) Sister = 2 (8%) Son = 1 (4%) Parent = 1 (4%) Brother = 1 (4%)	Cancer	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Grounded theory approach Stress and coping framework Constant comparative analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High
51	Kuşçu et al. (2009)	Turkey	To = explore pathways of becoming an informal caregiver, individual motives and contextual factors that contribute to this role during cancer treatment.	59	Female: 42.7 (NR) Male: 41.4 (NR)	49 (83%)	Turkish = 59 (100%)	Spouse = 22 (37%) Children = 20 (34%) Sibling = 7 (12%) Relative = 7 (12%) Others = 3 (5%)	Cancer	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR NR Qualitative content analysis	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	15 Moderate
52	Lauritzen et al. (2019)	Denmark	To explore carer participation in support groups when caring for a person with dementia who lives at home.	25	NR (40–82)	19 (76%)	Danish = 25 (100%)	Spouses Siblings Father/husband Daughters Daughter-in-law Neighbour	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews and focus groups	Ethnographic approach NR Inductive content analysis	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources	18 High
53	Lee et al. (2019)	South Korea	To explore the experiences of families who care for older adults with non-cancer diseases at the end of their lives.	9	64.5 (56-79)	7 (78%)	Korean = 9 (100%)	Daughter = 4 (44%) Son = 2 (22%) Wife = 2 (22%) Daughter-in-law = 1 (11%)	Dementia and bedsores = 6 (67%) Cerebral infarction and renal failure = 1 (11%) Amyotrophic lateral sclerosis = 1 (11%) Bedsores = 1 (11%)	NR (10 months – 33 years)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Phenomenological approach Cultural perspective Giorgi's phenomenological method	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources	19 High
54	Leichtentritt et al. (2004)	Israel	To explore the experiences of Israeli Moslem caregivers of family members suffering from cognitive decline.	18	61+ (NR)	12 (67%)	Arab-Moslem = 12 (100%)	Children, neighbours, and family members (e.g., siblings, sister-in-law).	Dementia/ cognitive decline	NR (2-5 years)	NR	NR	Purposive	Cross-sectional, face-to-face and joint (family) semi-structured interviews	Hermeneutic phenomenological approach Ethnic perspective Hermeneutic phenomenological analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship	18 High
55	Lewis et al. (1995)	USA	To describe the experience of carers living with their elderly parents and their needs.	5	NR (35-73)	5 (100%)	NR	Daughter = 5 (100%)	NR	NR (18 months – 18 years)	NR	3 (60%)	Purposive	Cross-sectional, face-to-face semi-structured interviews	Ethnographical approach NR Field and Morse's method of data analysis	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	15 Moderate
56	Li et al. (2012)	China (Shandong)	To understand what older Chinese people	23 (12 rural CGs,	Rural CGs:	Rural CGs: 8 (36%)	Chinese = 22 (100%)	Rural CGs: Wife = 4 (33%) Son = 4	Heart disease = 6 (25%)	NR	NR	NR	Purposive	Cross-sectional,	NR NR	Societal norms and perceived expectations The nature of relationship	19 High

			with chronic illness and their family caregivers perceive to be good care, and to compare perspectives of those living in rural and urban areas.	11 urban CGs)	53 (29–74) Urban CGs: 65 (43–74)	Urban CGs: 7 (32%)		Daughter = 1 (8%) Daughter-in-law = 3 (25%) Urban CGs: Husband = 3 (27%) Wife = 5 (45%) Son = 1 (9%) Daughter-in-law = 2 (18%)	Diabetes = 4 (17%) Stroke = 3 (13%) Bronchitis =3 (13%) Hypertension = 2 (8%) Other = 6 (25%)					face-to-face semi-structured interviews	Thematic content analysis	Contextual aspects of caregiving	
57	Lin et al. (2012)	UK	To explore the changes in the carers' experiences of looking after a relative living with dementia, and the effects of caring on the carers' autonomy.	6	67 (64-72)	3 (50%)	NR	Spouse = 6 (100%)	Dementia	NR (6-10 years)	NR	NR	Purposive	Longitudinal, face-to-face and one-to-one semi-structured interviews	Grounded theory approach NR Constant comparative analysis	The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	19 High
58	Mahilall (2006)	South Africa (KwaZulu-Natal Province)	To explore needs, motivations and expectations home based carers caring for HIV/AIDS care recipients.	First time point – 25; Second time point - 30	First time point – NR (20-50); Second time point - NR (20-50)	First time point – 24 (96%); Second time point - 28 (93%)	African = 55 (100%)	First time point – Non-relative = 25 (100%); Second time point – Non-relative= 30 (100%)	AIDS	First time point – NR (0-5 years); Second time point – NR (1,5 – 5+ years)	Some participants volunteered providing care before.	NR	Random	Longitudinal, face-to-face, semi-structured focus groups	Participatory action approach NR NC (Thematic or qualitative content analysis)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High
59	Mars (2015)	USA	To explore the experience of African American informal caregivers of family members with Alzheimer's Disease and Related Dementia (ADRD).	16	62 (50-85)	14 (88%)	African American = 16 (100%)	Daughter = 8 (50%) Spouse = 4 (25%) Sister = 3 (19%) Son = 1 (6%)	Alzheimer's Disease and Related Dementia (ADRD)	NR (1-15 years)	NR	9 (56%)	Purposive	Longitudinal, face-to-face and one-to-one semi-structured interviews	Descriptive phenomenology Caregiver identity theory Colaizzi's (1978) Method of Analysis	The nature of relationship Personal characteristics, beliefs and resources	15 Moderate
60	McDermott and Mendez-Luck (2018)	USA (California)	To understand the experiences of caregiving role and responsibilities in a sample of Mexican-origin caregiving women living in California.	44	NR (23-89)	44 (100%)	Mexican-origin = 44 (100%)	Wife = 12 (27%) Non-spousal relative (daughter, daughter-in-law, granddaughter) = 32 (73%)	Most frequently reported: diabetes, dementia, and physical impairments that compromised care recipients' mobility.	8.3 years (NR)	NR	Most unemployed (84%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR Cultural Psychological Perspective Thematic analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	20 High
61	McDonell et al. (1991)	USA	To assess family members' willingness to care for a person with AIDS.	2	NR	1 (50%)	American = 2 (100%)	Mother = 1 (50%) Father = 2 (50%)	AIDS	NR	NR	NR	NR	NR	Case study Model of willingness to care NR	N/A	9 Low
62	McDonnell and Ryan (2014)	Ireland	To explore the experiences of sons caring for a parent with dementia.	13	48 (32-60)	0 (0%)	Caucasian = 13 (100%)	Son = 13 (100%)	Dementia	NR (2-5 years)	NR	10 (77%)	Purposive	Cross-sectional, one-to-one semi-structured interviews	NR NR Colaizzi's (1978) seven-stage analysis	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	18 High
63	Mendez-Luck and Anthony (2016)	USA (California)	To explore how women of Mexican-origin conceptualize	44	53 (23-89)	44 (100%)	Mexican-origin = 44 (100%)	Wife = 12 (27%) Non-spousal relative	Most frequently reported: diabetes,	8.3 (8 months to 62 years)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one	Grounded theory approach Cultural perspective	Cultural values and beliefs The nature of relationship	17 Moderate

			caregiving in terms of cultural beliefs, social norms, role functioning, and familial obligations.					(daughter, daughter-in-law, granddaughter) = 32 (73%)	dementia, and physical impairments that compromised care recipients' mobility					semi-structured interviews	Constant comparative method		
64	Merrill (1996)	USA, New England	To examine transition into the role of a carer with the emphasis on the cooperation or conflict between siblings and class differences.	40	NR (45-64) (75% of the participants in this age range)	33 (82%)	White = 40 (100%)	Adult child = 40 (100%)	NR	NR (1-4) years (for 60% of the participants)	NR	30 (75%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR NR Content analysis	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	14 Moderate
65	Meyer et al. (2015)	USA	To explore the experiences of Vietnamese caregivers caring for a family member with dementia.	10	55 (37-86)	7 (70%)	Vietnamese = 10 (100%)	Adult child = 8 (80%) Spouse = 2 (20%)	Dementia	NR	NR	1 unemployed	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews and focus groups (which followed the individual interviews)	NR Cultural perspective NC (Grounded theory analysis)	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources	19 High
66	Mok et al. (2003)	China	To describe the impact of being the main caregiver for a terminally ill patient.	24	48 (19-68)	21 (88%)	Chinese = 24 (100%)	Spouse = 17 (71%) Mother = 6 (25%) Friend = 1 (4%)	Cancer	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Grounded theory approach Constant comparison analysis	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources	19 High
67	Morgan and Laing (1991)	Canada	To explore the impact of diagnosis of Alzheimer's disease from the perspective of caregiving spouse.	9	NR	6 (67%)	NR	Spouse = 9 (100%)	Alzheimer's disease	NR	NR	NR	Purposive	Cross-sectional, face-to-face or telephone and one-to-one unstructured interviews	Grounded theory approach NR Constant comparison analysis	The nature of relationship	16 Moderate
68	Muoghalu and Jegede (2010)	Nigeria	To examine the role of culture and the family in the care for PLWHA in Anambra State.	10	18+ (NR)	4 (40%)	African = 10 (100%)	NR	AIDS	NR	NR	NR	Random	NR	NR NR NC	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	14 Moderate
69	Murphy (2005)	USA (Texas)	To describe the positive or beneficial aspects of caregiving.	11	Men: 79 (NR) Women: 56 (NR)	8 (73%)	White American = 5 (45%) Hispanic = 6 (55%)	Male spouse = 3 (27%) Adult daughter = 7 (64%) Daughter-in-law = 1 (9%)	Alzheimer's disease	2.5 years (NR)	NR	6 (55%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews (3 interviews have follow-up)	Phenomenological approach Stress and coping models, existential perspective, social constructionism Content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	19 High
70	Neufeld and Harrison (1998)	Canada	To explore reciprocity in the relationships of men caring for an older person who is cognitively impaired.	22 (individual interviews) 7 (focus group)	Individual interviews - NR (33-87) Focus group – NR (33-72)	0 (0%)	NR	Individual interviews: Husband = 16 (73%) Son, son-in-law or grandson = 5 (23%) Brother = 1 (5%) Focus group: Husband = 5 (72%) Son = 1 (14%) Grandson = 1 (14%)	Cognitive impairment - Alzheimer's disease, vascular dementia, undisclosed source of cognitive impairment	NR (2-18 years)	NR	NR	Purposive	Longitudinal, face-to-face and one-to-one semi-structured interviews and a focus group	Grounded theory approach Exchange and equity theories Grounded theory analysis	The nature of relationship Personal characteristics, beliefs and resources	19 High

71	Ng et al. (2016)	Singapore	To explore the motivations, challenges and cultural aspects of family caregiving for cancer in Singapore.	20	45 (21-64)	12 (60%)	Singaporean = 17 (85%) Asian (raised outside Singapore) = 3 (15%)	Child = 9 (45%) Spouse = 4 (20%) Other family member = 7 (35%)	Cancer	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR Motivational models, cultural perspective Thematic analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	19 High
72	Nkongho and Archbold (1995)	USA	To explore American African carers' reasons for caregiving.	17	62 (35-81)	14 (82%)	African American = 17 (100%)	Spouse Grandchild Child Sibling Other relative Friend	Various - Alzheimer's disease, stroke, cancer, diabetes, heart disease, arthritis, sensory problems, multimorbidity.	8 years (9 months- 19 years)	6 (35%) were previously carers for other family members	NR	Purposive	Cross-sectional, one-to-one semi-structured interviews	NR Motivational perspective NC (Grounded theory analysis)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	17 Moderate
73	Öhman and Söderberg (2004)	Sweden	To elucidate the meaning of close relatives' experiences of living with a person with serious, chronic illness.	14	74 (48-80)	14 (100%)	Swedish = 14 (100%)	Spouse = 13 (93%) Daughter = 1 (7%)	Various - Cancer, lung disease, heart failure, or neurological (e.g., dementia and stroke), rheumatological, or kidney disease.	NR	NR	0 (0%)	Purposive	Cross-sectional, face-to-face and one-to-one unstructured interviews	Phenomenological hermeneutic approach NR Phenomenological hermeneutic analysis	The nature of relationship Personal characteristics, beliefs and resources	18 High
74	Opie (1994)	New Zealand	To explore the gender differences in caregiving.	28	NR	18 (64%)	NR	Wife = 7 (25%) Husband = 6 (21%) Daughter and daughter-in-law = 11 (54% Son = 4 (14%)	Dementia	NR	NR	9 (32%)	Purposive	Longitudinal, face-to-face and one-to-one unstructured interviews	Gender theory NR Content analysis	The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	16 Moderate
75	Øydgard (2017)	Norway	To explore institutional discourses on the work of informal carers.	26	NR	23 (88%)	Norwegian = 26 (100%)	Spouse = 9 (35%) Adult child = 13 (50%) Other (sister, cousin, friend) = 4 (15%)	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Ethnographic approach Social policy framework NR	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	14 Moderate
76	Pang and Lee (2019)	China	To explore the caregiving experience of spousal caregivers of persons with YOD in Hong Kong.	6	67 (61–73)	3 (50%)	Chinese = 6 (100%)	Spouse = 6 (100%)	Young-onset dementia (YOD)	3.5 years (1-6)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Qualitative descriptive Cultural perspective Qualitative content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High
77	Park (2012)	USA	To explore how Confucian notions of filial piety and parental obligation shape caregiving in Korean immigrant families.	6	52.8 (38-68)	6 (100%)	Korean American = 6 (100%)	Mother = 4 (67%) Daughter-in-law = 1 (17%) Sister = 1 (17%)	'Mental illness' – Schizophrenia, Depression, Dementia, ADHD	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Interpretive phenomenological approach Cultural perspective Thematic analysis	Cultural values and beliefs The nature of relationship	15 Moderate

78	Park (2015)	New Zealand (but the study concerns Korea)	To explore the Act on the Encouragement and Support of Filial Piety and other related laws.	0 (documents)	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	Purposive	Key documents in Korean social policy (Act on the Encouragement and Support of Filial Piety and other related laws)	Qualitative documentary research NR Thematic analysis mixed with a chronological narrative	Cultural values and beliefs Societal norms and perceived expectations	15 Moderate
79	Parveen et al. (2011)	UK	To explore the experience of British South-Asian sub-ethnic groups (British-Bangladeshi, British-Indian and British-Pakistani) caregivers and compare with White-British caregivers.	30	NR (24–80)	28 (93%)	British-Bangladeshi (BB) = 8 (27%) British-Indian (BI) = 9 (30%) British-Pakistani (BP) = 4 (13%) White-British (WB) = 9 (30%)	Spouse = 18 (60%) Daughter = 2 (7%) Daughter-in-law = 5 (17%) Parent = 4 (13%) Other = 1 (3%)	Cancer = 5 (17%) Dementia = 12 (40%) Stroke = 6 (20%) Multiple = 1 (3%) Other = 6 (20%)	BB = 8.31 (NR) BI = 11.14 (NR) BP = 7 (NR) WB = 18.75 (NR)	NR	NR	Purposive	Cross-sectional, face-to-face and semi-structured focus groups	NR Stress and coping models Thematic content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	19 High
80	Pelusi (1999)	USA	To describe the experience of being a partner of a long-term breast cancer survivor.	7	55 (42-76)	2 (29%)	Caucasians = 3 (43%) Afro-American = 1 (14%) Hispanics = 2 (29%) Asian-Pacific Islander = 1(14%)	Spouse/'domestic partner' = 7 (100%)	Breast cancer	NR	NR	NR	Purposive	Cross-sectional, face-to-face and semi-structured interviews	Phenomenological approach Quality of life models Colaizzi's eight-step method of analysis	The nature of relationship Personal characteristics, beliefs and resources	14 Moderate
81	Pierce (2001)	USA (Ohio)	To examine caregivers' experience and the meaning of caring as it influences their ability to care for persons with stroke within their African American family systems.	24 (8 primary CGs, 16 secondary CGs)	Primary CGs: NR (26-76) Secondary CGs: NR (22-65)	20 (83%)	African American = 24 (100%)	Husband = 2 (8%) Son = 2 (8%) Wife = 3 (13%) Daughter = 12 (50%) Granddaughter = 1 (4%) Daughter-in-law = 1 (4%) Sister = 2 (8%) Friend = 1 (4%)	Stroke	NR (6 months to 11 years)	NR	NR	Purposive	Cross-sectional, face-to-face and semi-structured interviews	Ethnographic approach Cultural perspective Theory-driven analysis	The nature of relationship Personal characteristics, beliefs and resources	18 High
82	Piotrowska (2015)	Poland	To explore problems of families looking after terminally ill relatives, their causes, family motivation for care, ways of managing caregiving.	10	NR (43-75)	NR	Polish = 10 (100%)	Wives, husbands, daughters, a mother and a nice.	NR	NR (2-40 years)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR Kubler-Ross's model of grieving NR	N/A	11 Low
83	Qadir et al. (2013)	Pakistan	To explore awareness caregivers' attitudes toward family members suffering from dementia, and their experience of burden.	12	34 (19–47)	7 (58%)	Pakistani = 12 (100%)	Daughter = 5 (42%) Son = 3 (25%) Daughter in-law = 2 (17%) Grandson = 1 (8%) Nephew = 1 (8%)	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR NR NR	Cultural values and beliefs Societal norms and perceived expectations	17 Moderate
84	Qiu et al. (2018)	China (Jiangsu Province)	To explore and describe the caregiving experiences and the impact culture on these in a sample of Chinese stroke caregivers.	25	66 (45–82)	19 (76%)	Chinese = 25 (100%)	Spouse = 16 (64%) Child or child-in-law = 9 (36%)	Stroke	6 months (NR)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Qualitative descriptive Cultural perspective, stress and coping models Content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	19 High

85	Quinn (2009)	UK	To explore issues of caregiver motivations to provide care, relationship quality and the meaning in caregiving.	12	65 (41-86)	6 (50%)	White British = 12 (100%)	Spouse = 8 (67%) Adult-child = 4 (33%)	Dementia	NR	NR	0 (0%)	Purposive	Cross-sectional, one-to-one semi-structured interviews	Qualitative exploratory Equity and Commitment theories, meaning-making in caregiving Interpretative Phenomenological Analysis (IPA)	The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	17 Moderate
86	Rivera et al. (2009)	Spain	To understand the cohabitation arrangements, rotation and the rejection of long-term care institutions in families of people with dementia in Spain.	16	NR	13 (81%)	Spanish = 16 (100%)	NR	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews and focus groups	Phenomenological approach NR Interpretative analysis	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	15 Moderate
87	Russell (2001)	USA	To explore caregiving experiences of elderly men.	14	NR (68–90)	0 (0%)	White American = 11 (79%) White European = 2 (14%) African American = 1 (7%)	Husband = 14 (100%)	Dementia	NR	NR	2 (14%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR Gender perspective NC (‘Inductive analysis’)	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	16 Moderate
88	Sand et al. (2010)	Sweden	To investigate caregiving motives.	20	58 (16–79)	12 (60%)	Swedish = 20 (100%)	Spouse = 12 (60%) Child = 6 (30%) Parent = 1 (10%) Sibling = 1 (10%)	NR (Various)	NR	NR	14 (70%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Hermeneutical approach Existential perspective Existential hermeneutics analysis	The nature of relationship Personal characteristics, beliefs and resources	19 High
89	Sasat (1998)	UK	To explore the nature of caring for elderly demented relatives living at home in Thailand.	44	56.2 (25-85)	35	Thai = 44 (100%)	Spouse = 24 (54%) Adult Child = 14 (32%) Niece = 1 (2%) Daughter -in-law = 5 (11%)	Dementia	NR	NR	15 (43%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR Stress and coping models NC (Narrative analysis)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	16 Moderate
90	Sheu (1997)	USA	To explore the meaning of Chinese filial piety (Hsiao) and cultural beliefs within filial caregiving experiences.	16	NR (31-46)	10 (63%)	Chinese(-American) = 16 (100%)	Adult child = 16 100%)	Various - Depression, Dementia, Stroke, Heart disease, Diabetes	NR	NR	9 (56%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Grounded theory Motivational perspective Constant comparative analysis (with Clarke's reframing of grounded theory analysis)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	20 High
91	Spitzer et al. (2003)	Canada	To explore the experiences of immigrant women in Canada who are caring for family members with chronic health problems.	29	50 (29-75)	29 (100%)	Chinese = 18 (62%) South Asian Canadian = 11 (38%)	Daughter-in-law = 7 (28%) Daughter = 9 (31%) Spouse = 7 (28%) Mother = 6 (24%)	Various - cancer, kidney or heart disease, dementia, or arthritis, cerebral palsy and developmental delay	NR	NR	19 (66%)	Purposive	Cross-sectional, face-to-face semi-structured interviews	Ethnographic approach Cultural perspective Content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	16 Moderate
92	Stajduhar et al. (2008)	Canada	To describe factors that influence family caregivers’ ability	29	65 (40-85)	26 (90%)	(Western-)Canadian = 29 (100%)	Spouse = 22 (76%) Adult child = 3 (10%)	Cancer	NR (<3 months – 12+ months)	NR	8 (28%)	Purposive	Cross-sectional, face-to-face and one-to-one	Interpretive descriptive approach	The nature of relationship Personal characteristics, beliefs and resources	17 Moderate

			to provide end-of-life cancer care at home.					Sibling = 3 (10%) Parent = 3 (10%)						semi-structured interviews	NR Thematic analysis	Contextual aspects of caregiving	
93	Statham (2003)	UK	To explore why carers continue their role without support from formal service providers.	Phase 1 – 26 Phase 2 – 21, Phase 3 - 17	58 (36-83)	22 (85%)	NR	Daughter = 13 (50%) Daughter-in-law = 2 (8%) Spouse = 8 (31%) Son = 2 (8%) Sister = 1 (4%)	NR	6.88 (6 months to 20 years)	NR	5 (19%)	Purposive	Longitudinal, face-to-face and one-to-one semi-structured interviews plus focus groups	Grounded theory Theories of care, stress and coping models Grounded theory analysis	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	18 High
94	Sterritt and Pokorny (1998)	USA	To explore the meaning of caregiving to African-American caregivers of family members with Alzheimer's disease.	9	54 (31–80)	8 (88%)	African-American = 9 (100%)	Daughter = 5 (56%) Brother = 2 (22%) Wife = 1 (11%) Granddaughter = 1 (11%)	Dementia	4.8 years (3– 8)	NR	NR	Purposive	Cross-sectional, semi-structured interviews	NR NR NC (Thematic analysis)	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	17 Moderate
95	Strumpf et al. (2001)	USA	To describe and compare Cambodian, Vietnamese, Soviet Jewish, and Ukrainian refugee caregivers on life experiences, health status, and knowledge of available services.	105	NR (20-71)	105 (100%)	Cambodian = 30 (29%) Vietnamese = 30 (29%) Soviet Jew = 30 (29%) Ukrainian = 15 (14%)	NR (Different)	Various - high blood pressure, “rheumatism”, arthritis, insomnia, nervousness, headaches, stroke, emphysema, asthma, glaucoma, stomach ulcers, anaemia, memory problems, heart and circulation problems, cataracts, kidney and gallbladder problems, constipation	NR	NR	‘Unemployment was considerable’	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR NR Content analysis	Cultural values and beliefs The nature of relationship Contextual aspects of caregiving	17 Moderate
96	Sung (1994)	USA (New York) and Korea (Seoul)	To compare filial motivations of Korean caregivers with those of American caregivers.	375	USA: 51 (NR) Korea: 48 (NR)	USA: 162 (80%) Korea: 146 (85%)	American = 203 (54%) Korean = 172 (46%)	USA: Adult child = 132 (65%) Spouses, siblings, nieces or nephews = 71 (35%) Korea Adult child = 157 (91%) (sons = 13%, daughters-in-law = 74%, daughters = 12%) Other = 15 (9%)	NR	NR	NR	NR	Random	Cross-sectional, open-ended survey (sent out to participants)	NR Cultural perspective, Motivational models Content analysis	Cultural values and beliefs The nature of relationship	12 Low
97	Takigiku et al. (1993)	USA	NR	1	A person in their ‘late 50s’	1 (100%)	White = 1 (100%)	Mother = 1 (100%)	AIDS	NR	NR	1 (100%)	NR	Cross-sectional (NR)	Case study Stress and coping framework NR	N/A	10 Low
98	Tretteteig et al. (2017a)	Norway	To explore the situation of family	17	66 (46-86)	12(71%)	Norwegian = 17 (100%)	Son = 3 (18%)	Dementia	NR	NR	2 (12%)	Purposive	Cross-sectional,	Qualitative descriptive	The nature of relationship	20

			caregivers and to examine to what extent day care centres (DCCs) can meet their need for support and respite.					Daughter = 5 (29%) Wife = 6 (35%) Daughter-in-law = 1 (6%) Husband = 2 (12%)						face-to-face and one-to-one semi-structured interviews	NR Systematic text condensation (Malterud, 2012)	Personal characteristics, beliefs and resources	High
99	Tretteteig et al. (2017b)	Norway	To explore family caregivers' experiences of meaning and motivation in their caring role.	5	71 (54-87)	3 (60%)	Norwegian = 5 (100%)	Son = 1 (20%) Daughter = 1 (20%) Wife = 2 (40%) Husband = 1 (20%)	Dementia	NR	NR	4 (80%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Narrative approach Motivational models Narrative analysis	The nature of relationship Personal characteristics, beliefs and resources	18 High
100	Van Sjaak Geest (2002)	Ghana (Kwahu)	To explore caregiving obligations towards elderly people in a rural town of southern Ghana.	35	NR	NR	African = 35 (100%)	NR (Various)	NR	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews plus focus groups	Interpretative ethnographic approach Caring concepts Ethnographic descriptive analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship	15 Moderate
101	van Wezel et al. (2016)	Netherlands	To explore the experiences of female Turkish, Moroccan and Surinamese Creole family carers in the Netherlands about providing family care to a close relative with dementia.	69	NR (20–84)	69 (100%)	Turkish = 26 (38%) Moroccan = 26 (38%) Surinamese = 17 (24%)	Daughter = 55 (80%) Daughter in-law = 9 (13%) Wife = 3 (4%) Other = 2 (3%)	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews plus focus groups	Generic approach NR NC	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship	17 Moderate
102	Vellone et al. (2002)	Italy	To explore the experience of Italian caregivers of people with Alzheimer's Disease.	26	57 (35–86)	20 (77%)	Italian = 26 (100%)	Spouse = 19 (73%) Adult child = 7 (27%)	Alzheimer's Disease	5 years (2–9)	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Hermeneutic phenomenological approach NR Phenomenological analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	17 Moderate
103	Wallhagen and Yamamoto-Mitani (2006)	USA, Japan	To explore the cultural impact on the experiences of daughter (or daughter-in-law) caregivers of elderly persons with dementia by comparing caregivers in the United States and Japan.	16 (9 American and 7 Japanese)	Japanese = 54 (47–57) American = 49 (41–63)	16 (100%)	American = 9 (53%) Japanese = 7 (47%)	Daughter = 12 (75%) Daughter in-law = 3 (19%) Niece = 1 (6%)	Dementia	NR	NR	NR	Purposive	Longitudinal, face-to-face and one-to-one semi-structured interviews	NR Cultural perspective Constant comparative analysis	Cultural values and beliefs The nature of relationship Personal characteristics, beliefs and resources	17 Moderate
104	Wallroth (2016)	Sweden	To explore men's motivations to provide care for their elderly parents and their caregiving experiences.	19	58 (32-72)	0 (0%)	Swedish = 19 (100%)	Adult son = 17 (89%) Son-in-law = 2 (11%)	NR	7.5 years (2-20 years)	NR	3 unemployed	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Phenomenological approach Caring concepts, motivational perspective Giorgi's phenomenological analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	20 High
105	Weinland (2009)	USA	To explore the experience and motivations of African American men providing care to a relative at home setting.	10	NR (39 – 79+)	0 (0%)	African American = 10 (100%)	Husband = 4 (40%) Father = 2 (20%) Son = 3 (30%) Grandson = 1 (10%)	NR	NR	NR	7 (70%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Phenomenological approach NR Descriptive phenomenological analysis	Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	18 High

106	Wiles (2002)	Canada	To examine motivations to care, the experience and meaning of caregiving at home.	30	NR (40-87)	23 (77%)	NR	Wife = 14 (47%) Daughter = 9 (30%) Husband = 5 (17%) Son =2 (7%)	Various – 'increasing frailty and dependence', stroke, heart attack, diabetes, Parkinson's, Alzheimer's, Multiple Sclerosis	NR (1-30 years)	NR	9 (30%)	Purposive	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Narrative approach Relational perspective, theory of space and planning Narrative analysis	Societal norms and perceived expectations The nature of relationship Contextual aspects of caregiving	16 Moderate
107	Williams et al. (2014)	UK	To explore how family caregivers cope and make sense of caregiving.	13	NR (3-73)	12 (92%)	British = 13 (100%)	Wife = 5 (38%) Daughter = 7 (54%) Friend = 1 (8%)	Stroke = 5 (38%) Dementia = 8 (62%)	NR (6 months to 10 years)	NR	NR	Purposive	Cross-sectional, semi-structured interviews	Phenomenological and photovoice approach Stress and coping models Interpretative Phenomenological Analysis (IPA)	The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	18 High
108	Yamamoto and Wallhagen (1997)	Japan	To understand why family carers of demented elderly continue caregiving despite various caring difficulties.	26	NR (32–63)	26 (100%)	Japanese = 26 (100%)	Daughter = 13 (50%) Daughter in-law = 13 (50%)	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face and one-to-one unstructured and semi-structured interviews	NR Cultural and existential perspective Constant comparative analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources Contextual aspects of caregiving	17 Moderate
109	Yeo et al. (2002)	USA	To explore the experiences of Vietnamese caregivers of elderly with dementia.	9	NR (28-72)	5 (56%)	Vietnamese American = 9 (100%)	Wife = 1 (11%) Husband = 2 (22%) Son = 2 (22%) Daughter = 3 (33%) Niece = 1 (11%)	Dementia	NR	NR	NR	Purposive	Cross-sectional, face-to-face semi-structured interviews	NR NR Content analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	17 Moderate
110	Zhang and Lee (2019)	China	To explore the meaning of the experience of the Chinese family caregivers of stroke survivors.	5	52 (26-75)	3 (60%)	Chinese = 5 (100%)	Spouse = 3 (60%) Daughter = 1 (20%) Son = 1 (20%)	Stroke	NR (1 month to 2 years)	NR	3 (60%)	Purposive	Cross-sectional, face-to-face unstructured interviews	Hermeneutic phenomenological approach Cultural perspective, meaning-making in caregiving Phenomenological hermeneutic analysis	Cultural values and beliefs Societal norms and perceived expectations The nature of relationship Personal characteristics, beliefs and resources	20 High

NR - Not reported; **N/A** - Not applicable; **NC (*)** – Not clear (first reviewer's assumption regarding the method of data analysis)

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A13 Appendix - Findings with overinclusive quotes. A long version of qualitative findings with overinclusive list of supporting caregiver quotes.

Theme 1: Contextual aspects of caregiving

This theme highlights the importance of the wider situational and temporal context within which caregiving is situated. Two broadly defined categories consisted of four main subthemes. Firstly, caregiving context embrace: convenience factors; dependence on the care recipient; and competing priorities and demands; and secondly, temporal aspects of caregiving which reflect fluctuations in caregiving motivations. These contextual subthemes (1.1 and 1.2) affect the extent to which the later described themes (discerned on relational and personal levels as well as cultural and societal levels described elsewhere) have salience/dominance in terms of shaping caregiver motivations and willingness to provide care.

1.1 Caregiving context

1.1.1 Convenience factors

Convenience factors are understood as those making the caring role possible or necessary, such as: being the only child; being single; being the last sibling to get married and leave home; bringing a widowed parent into one's home or moving back to stay with parents after divorce; flexibility to accomodate careigiving with existing employment comitments, not having young children, geographical proximity, material space and personal and financial means to provide care. Four wider factors were developed from caregiver accounts: (a) the role of geographical proximity; (b) caregiver's own situation for providing care; (c) family structure; (d) living with the care recipient [1–16].

(a) The distance to the care receiver – geographical proximity - shapes the way that people can provide care, with some carers expressing that living close to the care recipient may have enabled increased motivation and informal care provision [1,2,9–11].

'It just naturally fell on the ones that are closest to the [elders] home.' [1]

(b) Aspects of the caregiver's own situation – available space, financial and personal means, their own situation (e.g., retired/ unemployed, having no competing caring or employment responsibilities) [3,11–16].

'We're four girls and two boys. I happen to be the most available because I don't work and my son is 24, so I'm free with my time. And my husband's dead.' [13]

'No we haven't discussed it. I am the youngest daughter, divorced and have no children, so I decided to take care of my mother.' [16]

(c) Absence of siblings or other family members also determined motivations and willingness to provide care [4–7,9] which links to the later discussion of the perceived choice in undertaking informal caregiving duties (see subtheme 4.4).

'I already knew that one day I'd be taking care of them . . . You see, there's nobody, except me.' [5]

'I pretty much did it because I'm the only child.' [6]

(d) In one study [8] it was reported (as the second-order construct) that daughters were more likely to have taken on caregiving obligations when they had been living with their parent for a considerable time period.

1.1.2 Dependence on the care recipient

The subtheme describes a socioeconomic reliance on the care recipient existed, for example, some carers were dependent socioeconomically on the care recipient at the current time or out of hopes to inherit the care recipient's assets in the future. These types of factors are linked to extrinsic motivations in providing care [13,17–19].

'I'm her slave, a slave of circumstances…' [13]

'She doesn't want to go to a home. Not at all, she absolutely refuses. . .' [13]

1.1.3 Competing priorities and demands

A struggle to balance busy personal and professional lives and caregiving roles (sometimes referred to as the 'responsibility conflict'), conflicting demands and the burden that arises from this describes this subtheme.

Competing priorities, demands and beliefs comprised a subtheme which refers to difficulties encountered when combining care responsibilities with employment; or an imbalance in competing familial role demands (described as limiting their ability to act '*like a member of the family'*) [15,20–24]. Adult children caregivers often reported a conflict between the responsibility of caregiving for an elderly parent and that of their nuclear family and/or of work (sandwich population); spouse caregivers reported balancing their own physical (i.e. own physical health and limitations) and psychological needs with their care recipient's needs [5,21,23–33].Having paid employment was found to constrain motivations to care and comprised a source of tension, heightened if the sociocultural context imposed expectations of caregiving (e.g., filial piety) [15,20–24].

'Every day, I struggle with two choices: to work and let my dad go to the hospital alone, or to

accompany him and have no money to pay the bills.' [15]

'I had a conflict between caregiving work and outside full-time work. Finally, I quit my job because I would like to take good care of my mother....' [22]

The competing demands associated with multiple familial roles increased burden and negatively influenced caregiver motivations and willingness to provide care [5,21,23–33], especially for the 'sandwich generation' of caregivers.

'I am sort of in a unique situation, like the sandwich generation. I am a mother, grandma, and also a daughter. Of course, a wife too. I find it very difficult.' [25]

'I have a wife and kids, I am not putting my life on hold. I can't put my life on hold.' [26]

'I've got the boys at home, a husband and a dog...trying to keep up with everything' [21]

'It has affected my relationship with my children to a certain extent, because I cannot spend time with them. I cannot go anywhere. It is the same if they come home. He [her father] will get agitated.' [30]

'My husband needs me. My grandchildren need me. I am caught in the middle.' [5]

Interestingly, less often reported was the perceived competition between parental and filial caregiving priorities [27]. The provided primary data examples seem to be a reflection of a self-posed question: Whom should I provide with more care, my own children or my elderly parents?

'As a person, you only have 24 hours. You have to work, bring up your children, educate them, take care of their life and school. This will benefit their future and whole life. You can't say that you don't want to give them these. Then you have to take care of your aging parents because they did the same to you before. You have such responsibility. How do you coordinate all these three? I wanted to cover all of them. Even now I still want to cover them. However, how do I set my priorities? This is the problem I had struggled with. I think that educating your children is also very important, even more important than perhaps taking care of your aging parents. This is because eventually, they (the parents) will pass away. If you devote you full time to them, there won't be much use in the future. However, if you spent more time on your children, they will grow up better. That's why I could not put this thing (filial caregiving) on my priority list.' [27]

In addition the perceived burden arising from caregiving competing priorities and demands although treated as an outcome in many studies, was also noted to influence motivations and willingness to provide care over time, i.e. the experience was dynamic [9,21].

'Everything is put onto me.' [21]

'Well it has. Off course it has. You have got to set aside time for other things and such. And as I said, it can be tough sometimes. So, so therefore it is clear that one gets affected, so, one does. Now I see things in a different way.' [9]

1.2 Temporal aspects of caregiving

The dynamic and fluctuating nature of caregiving motivations at different stages of the 'caregiving career' was evident in the literature reviewed. The temporal orientation of caregiver motivations refers to different motivational factors that may be present at different stages of '*caregiving career'* or '*caregiver journey'*, i.e. different points in time subject to changes in care recipient's factors (e.g., symptoms, care needs) or caregiver's factors (e.g., their health, time). Motivations seemed to be dynamic, not fixed, and assigned to specific levels or orientations of motivations (expressed in subthemes presented) which were subject to changes depending on the caregiver and care recipient factors (including the dyadic context) [16,18,21,30,34–43]. Of the studies reviewed only sixteen reported longitudinal prospective data and some others also relied on retrospective accounts of change [12,21,32,35,39,40,42–50]. This subtheme draws from both types of data.

Using the term C*aregiving career* or the *caregiving journey* enables examination of the degree and nature of changing motives and relies on longitudinal data. Different factors influenced motivations to provide care at different stages, for example illness type, progression or relationship quality. For example, Hsu and Shyu (2003) in their study exploring social exchanges in informal caregivers in Taiwan described the changes in motivations starting from retrospective reciprocity motives, going through religiosity and expected reciprocity ending with being motivated by the pressure of social expectations when caregiving demands were higher.

Some carers described a previous or expected (future) shift from love and responsibility to seeking relief from the obligations and burden of care (i.e. relinquishing the caring role and finding alternative care arrangements). Caregivers expressed expectations of change due to awareness of a likely deterioration of their care recipient's health condition, including stated preparedness to care until the point at which alternative arrangements need to be considered [39,40]. Not all informal carers considered that the role became more demanding over time (regardless of the care-recipient's illness), with some considering that their role became easier over time due to the care duties becoming habitual – established routines - or perhaps by gaining more experience [18].

Overall, the reviewed evidence supports the presence of temporal shifts in motivations and willingness to provide care. Neither stability of motivation and willingness nor adaptation over time are inevitable given the often-unpredictable context of care and its associated demands. As evidenced, temporal changes in caregiving motivations might be intermediary factors in helping (or not helping) caregivers cope with their burden or even in influencing their willingness to provide care [18,34,38–43].

‘So, at first, caregiving was a challenge and I didn’t find it hard to do. After some years, there is wear and tear and the challenge is gone.’ [38]

‘You know, I shouldn’t say it, but I don’t think I would be able to [do caregiving]. No, I shouldn’t say that… I hope I would be able to, but I, I don’t think so cos I’m not a patient person.’ [40]

Caregiving motivations and willingness fluctuated depending on care recipient’s illness and needs as perceived by the caregiver whereby if the care recipient was said to be ‘doing well’, carers were better able to cope with the caring demands. Negative feelings seemed to be more likely reported by carers during times of high care recipient need rather than otherwise [16,21,30,35–37,43]. It also worth noting that in one case caregivers made applications to nursing homes based on the changing care recipient’s needs (higher demands) which was against their stated cultural and personal values inhibiting them from undertaking such action [30].

‘If he’s better, then I’m much better too. I think that’s probably why I’ve been coping quite well.’ [37]

‘The decision to have him into respite wasn't one that I took on me own, it wasn't just my decision it was my husband, my son, my daughter and yeah a little bit of myself because yeah I was ready for it I needed it.' [36]

‘I think we’ve reached the point where the benefits of being at home are probably not as great as they were’ [43]

Theme 2: The nature of the relationship

This analytic theme describes how motivations and willingness to provide care are influenced by relational factors, including emotions, cognitions (expectations) and behaviours central to familial relationships or relationships within the wider community. The theme incorporates five main descriptive subthemes: reciprocity; out of affection; relationship quality; family values; obligations to provide care.

2.1 Reciprocity

We distinguish between two different types of reciprocity present in the evidence provided by this systematic review:

- retrospective reciprocity – referring to the reciprocation of the past ‘debt’,
- expected reciprocity - describing caregiving investment with regards to a caregiver’s own children or other designated people in order to maintain or establish future support.

2.1.1 Retrospective reciprocity

This subtheme describes the reciprocation of the past ‘debt’ as a motivator in caregiving.

Retrospective reciprocity was repeatedly reported as one of the most prevalent determinants of motivations and willingness to provide care [1,4,7,9,10,13,15,16,19,20,25,35,39,41,45,47,49–68]. Within this, we could further distinguish between different forms as described below which were not mutually exclusive and proximate in their meaning. However, for the sake of consistency in presenting these different representations of retrospective reciprocity, we present them in an order which enables the terminological nuances and differences to be seen, with the reservation that some of these share similarities in some aspects. These various forms of retrospective reciprocity included: delayed reciprocity; constructed reciprocity; waived reciprocity; hypothetical reciprocity; and direct reciprocity.

Delayed reciprocity was a perceived imperative to repay or return past parental ‘investment’ and sacrifices, i.e. a perceived debt. Delayed reciprocity was most often identified in the reviewed studies as motivating the provision of support to parents [1,4,7,9,10,13,15,16,19,20,25,35,39,41,45–47,49–68].

‘My parents took care of me.. Because of that I had made myself a promise that I would take care of them.’ [51]
‘She looked out for me all my life and so it’s my turn now – to look after her.’ [54]

‘We did things for her she used to do for us.’ [1]

‘Because she had worked so hard we all thought it was our duty to care for her and met her needs. It is our desire to return happiness to her.’ [59]

‘She used to cook and prepare meals for us. It is our desire to make her happy now.’ [59]

‘I think it is not so easy to care for him, but he has undergone enormous hardship for us. It is only natural and right that we must care for him.’ [59]

Hypothetical, virtual or in-principle reciprocity posited that the care recipient ‘would’ help the giver if it was needed; often based on the feeling of shared understanding of the pre-existing caregiving relationship [10,38,42,56,69]. It was more characteristic of spousal/partner relationships, reflected an assumed reciprocity and was crucial in terms of initial motivations for caring.

‘You don't understand; if it was me who was ill, she would do double what I am doing for her.’ [56]

‘. . . I just say ‘she’d have done the same for me’. If it was me that had had the illness, you know, she’d have done the same for me.’ [42]

Spousal reciprocity was related to delayed reciprocity but with respect to spousal, not parental, ‘debt’. It was reflected in terms of a care recipient having taken care for the actual caregiver during past illness (a reverse in the situation) or having been a good spouse and therefore deserving to be cared for in the current circumstances [17,70,71].

‘I don’t think I would be able to leave him, when I think of all the wonderful things he has given me.’ [70]

‘He was a good husband. I’m sure that if it happened to me, he would do his best.’ [71]

Constructed reciprocity referred to non-verbal cues recognised by the caregivers as reflecting the care recipient’s implicit recognition of them and/or their effort (e.g., care recipient’s smile). In some cases the deterioration of an illness such as dementia resulted in the decline or disappearance of this type of reciprocity, although it is worth noting that that in some conditions, for example where communication was impaired, non-verbal reciprocity could acquire greater importance [72].

‘She looks more content when I am around. If I'm away for a week when I get back, the biggest smiles…’ [72]

‘It seems to do something for her because she seems content. There's something I'm sure gets through.’ [72]

Waived reciprocity related to situations where a care recipient could contribute little ‘back’ to the caregiver because of their condition, so caregivers ‘waived’ expectations of immediate reciprocity [72], i.e. they ‘waived’ or relinquished expectations of any immediate reciprocity due to the care recipient’s illness [72]. Therefore, in this type of retrospective reciprocity the desire to reciprocate (or to be reciprocated) was given less significance in the face of the care recipient's current needs.

‘My relationship with her now is as though she was a child and I was looking after her. You have to do what you have to do.’ [72]

Amongst the studies reviewed, retrospective reciprocity (a delayed reciprocity) is described using less scientific terms, i.e. ‘giving back’, ‘paying back’, ‘reciprocal love’, ‘reciprocating care’, ‘repaying family’, ‘repaying the debt to community’, ‘returning the love’, ‘gratitude’ or ‘showing gratitude’, ‘debt of heart’ or just ‘the debt’, ‘justice’. [3,5,9,14,17,22,27–29,39,44,45,57,65,73–79].

‘But it’s, it's my love for her. She has always supported me and been a really good friend so then, then, it’s like… my way of giving back. It's never been any… no, it, it was so, it felt so obvious… to support her. I have never, like, sat down and thought about it; it was something I wanted to do.’ [9]

‘I used to say that what you got from your parent, is what you want to give them back.’ [28]

‘It was my choice because he never mistreated me. He was always a good husband.’ [74]

‘She is my mother! When she was young, she worked very hard to bring me and my sisters up. Anyway, since I can remember, I felt that my mother’s and father’s lives were very, very difficult. I just feel I want to do things for them, to repay their love and upbringing. I have nothing to complain about.’ [77]

‘Now she is sick...it's time for me to care for her.’ [22]

‘I want to give something back to our people and community.’ [44]

‘She had me when she was a bit older. I was her precious son and I received more of her affection than my older sisters did. Therefore, to me, it made sense that I had to take care of her, and I don’t regret it.’ [78]

‘My mother nurtured me. She made very big sacrifices for us and she is not going to be here forever. So. I don't want her to leave this earth and not do my best for her. She made me who I am.’ [57]

‘Jesus, I was a bastard, I was always goin’ out with the guys from work. She was an angel . . . I was the bastard all the time . . . yeah, a real bastard (laughs) . . . you know, always blowin’ my cork, stuff like that . . . I used to go out a lot and raise all kinds of hell. Christ, this is the least I can do to try and make things right . . . and I wouldn’t have any other way.’ [65]

Direct reciprocity referred – according to social exchange theories [80,81] – to a direct, immediate or short-term form of reciprocity, occasionally reported by caregivers as a motivating factor [46,75]. For example, the care recipient helping look after the caregiver’s children for the care received.

‘The other thing that I should add is that, like right now my mom is giving to us and looking after the kids, and she feeds us once a week which . . . helps takes the pressure off of us a little bit.’ [46]

‘I brought her to live with us when she had a kidney problem last summer. After she got better she continued to stay with me. . . . She helps me fix dinner every night.’ [75]

Whilst most studies considered retrospective reciprocity as an important motivator, a contrasting view was also expressed by caregivers in two studies (one of which was exclusively interested with the caregivers’ perception of reciprocity) whereby reciprocity was considered insufficient to motivate the provision of informal care [31,46].

‘On some level, [reciprocity] could be a factor’, ‘I’m not thinking “oh gee, mom did this for

me and now I have to do it for her.' [46]

'She would be a recipient of that sense of debt that I owe. But even without that, it's . . . more than that. The other thing that I should add is that, like right now my mom is giving to us and looking after the kids, and she feeds us once a week which . . . helps takes the pressure off of us a little bit.' [46]

'But is that why I do it ... hm ... I wouldn't do it if that was all that was there?' [46]

'But I don't know – that feels not quite right. That's not really my motivation for doing it. Do I feel it now and again? Maybe that goes through my head but that's not my motivator.' [46]

Moreover, it should be highlighted that:

(a) 'Karma' can be also understood as a form of reciprocity but in the review it was coded separately as a 'religious or spiritual belief' influencing motivations to care [16,41];

(b) The concept of gratitude is closely related to reciprocity, but in some instances, it was conceptualised as more voluntary, intentional, and focused more on symbolic appreciation for past help rather than repayment [3,5,25,68].

(c) We can distinguish between two concepts similar to reciprocity– the concept of social/cultural debt (supraindividaully, e.g., present in Confucianism) and (retrospective or expected) reciprocity (individually) [7]. Reciprocity and exchange are underpinned to a large extent by cultural values (e.g., a Confucian-informed notion of filial piety, Buddhist doctrine of reciprocity, 'kathany ukatawethi' in the Thai context) [7,16,68].

(d) There are two other terms which are mentioned in the reviewed studies with reference to reciprocity but as second-order constructs. These are:

- Generalised reciprocity which had two different meanings – (a) it either referred to retrospective reciprocity describing exchanges in which exact, specific or in-kind repayment was not expected [46]; (b) or it was understood in terms of expected reciprocity as the expression of general social or altruistic values contributing to a larger good set as an example to caregiver children (it links with the subtheme '*Expected reciprocity*').
- Serial or stepwise reciprocity takes place in a situation when the 'return' is never received by the original giver may but it is reciprocated indirectly to a third party; an example is an adult child reciprocating 'debt' from their own parents by aiding, in return, their own offspring [10].

2.1.2 Expected reciprocity

This subtheme is concerned with caregiving investment with regards to a caregiver's own children or other designated people within and outside the immediate family network in order to maintain or establish future support.

Expected reciprocity describes a caregiving investment with an explicit view to maintaining or receiving future support, commonly the investment with regards to a caregiver's own child(ren). The term constructed by the authors (MZ, VM) seeks to bring together different synonymous terms found in the literature such as the demonstration effect, generalised reciprocity, or preparatory reciprocity which also involve providing support or care for parents in order to model or demonstrate their caregiving attitude to one's own children in anticipation of the need for future help and support [1,7,9,10,17,19,24,27,28,31,32,41,46,54,57,72,75,82–86].

The demonstration effect is a term most often used to describe caregiving investment with regards to a caregiver's own child(ren) in order to establish future caregiving support from them. It is synonymous to the generalised reciprocity (as presented in its second meaning before (see subtheme 3.1). Some carers supposed that if they did not take care of their parents, their children would not take care of them in the future either, thus they hoped that their care provision would elicit future mutual support. In a strikingly frequent manner this kind of investment was discussed prospectively by referring to one's future ageing when caregivers, thinking about themselves hypothetically, would need help and assistance from their family members [1,7,9,17,19,24,27,28,31,32,41,54,57,72,75,82–84].

'I love my parents very much and hopefully by caring for them I will get care back from my kids as an aging person.' [19]

'If something like that will happen to me, then I hope to be cared for at the same way I am caring for my mother.' [83]

'In about 10 years we'll be there, too, so I hope our kids do for us what we're doing for our parents.' [1]

'If you treat your father like this, you will be treated by your son in the same way some day.' [41]

'She provides what I like to see, what I would try to provide for my children, that there are going to be responsibilities, not so much to society, but in a larger sense.' [72]

Preparatory reciprocity also involves an investment through providing support or care for parents in order to model or demonstrate this to one's own children (such that these children might in turn support their parents in later years) but with more emphasis on instilling caring values than on getting care back in the future [10,44,46,85,86] and its actual conditional character where the investment is perceived less than a hope and more as a kind of warranty. Especially, in African context (Ghana) it was explicit and conditional (a prerequisite of accessing care) – if a parent did not care, then they may not expect the 'pay back'. It was a prerequisite of accessing care - those who worked hard for their children can be sure that they would receive respect and care from them [44]. From a societal level of understanding this may also serve as a form of cultural heritage maintaining the intergenerational care provision (setting examples to next generations). Certainly, this may be different in other countries where there is greater social and geographical mobility.

‘Caring for someone in old age is continuous work, it is not one day’s work, so in your old age you need your own children or children you helped to look after when they were young.’ [86]

‘If the parents looked after the children, no matter what will happen, the children will also care for their parents. Even where the children have travelled outside the town or outside Ghana, they will remit their parents. So all depends on the care the parents give to the children in their early years.’ [86]

‘If you take care of [your] older people now, then the younger people will take care of you when you grow old.’ [85]

‘As for my father, people [in the community] will understand if I don’t [provide any care or support] for him. He didn’t take care of [me and my siblings]; he didn’t pay for food, school fees and hospital bills.’ [85]

‘If I had kids I would expect them to look after me, as adults. Otherwise, why would you have them (laughing) – just kidding’. [46]

Moreover, depending on the cultural model of caregiving the investment may not need to be constrained to one’s own children as was the case in the data presented above – as in the Ghanaian example below where the desire to set the caregiving example to community is described [44]. This links to the analytic theme of ‘collectivist’ cultural values and beliefs presented elsewhere (see Part 1).

‘I want to be a good role model to the other youth and adults of my community so that they too can be uplifted.’ [44]

Some participants considered however that the demonstration effect was not a conscious/primary motivator for the support they provided their care recipients [46,52,69].

‘I mean I’m not a parent, but I was still shocked and I thought, why would you expect your kids to take care of you? . . . I don’t feel any obligation.’ [46]

‘My generation will be different. When we get old and sick, we’ll have long-term care, so we won’t depend on them [children] to take care of us. That’s a gift from us to them. They won’t have to go through this kind of agony and stuff.’ [69]

2.2 Out of affection

The subtheme relates to the feelings of affection discerned on emotional (e.g., deeply felt love), cognitive (e.g., love as decision) and behavioural levels (e.g., showing love) and encompasses a wide range of constructs such as love, emotional attachment or compassion [1–3,7,9,13,14,17–19,25,26,38–42,44–46,48,50,52,54–56,60,62,64–66,68–70,73,74,79,87–95]. Additionally, the perception of free choice was important in shaping the caregiving attitude – its presence promoted a desire to care (which can be considered as an intrinsic motivator) [17,18,34,42,45,66,79]. *Devotion to care (Caring from the heart), Determination to care and Showing love and responsibility* refers to the behavioural aspects of the theme - behaving in a way that expressed the affection through consuming the caregiver role [96] via wholehearted sacrifices (with examples described below) [5,21,22,33,36,40,43,45,48,57,61,66,68,73,76,77,87,90,97].

'It just comes from my heart.' [50]

'Those who don't mean anything to you don't represent care. Caring is something you do for those you hold dear or care about.' [9]

A sense of love towards the care recipient was prevalent and amongst the main motivations for providing care by caregivers. Described as love, deeply felt love, natural love and sometimes as fidelity, emotional connectedness/togetherness or emotional attachment (spousal, filial or other). Most carers derived motivation to provide care referring to affective properties of love (unconditional love, e.g., described as deeply felt love), while some perceived love as a cognition (conditional love, e.g., love as a decision with specific expectancies attached with regards to caregiving). With respect to the latter, caregiving was seen by some as an act of love within the relationship – internalised to the extent where love was discerned as the internal motivator, increasing caregiving commitment [1–3,9,13,14,17–19,26,38–40,42,44–46,48,54–56,62,64–66,68–70,73,74,79,90–94].

'Some people think love is a gushy thing. Love is a decision.' [17]

'It came . . .well, it's natural! I can't think of any precise reason, it just came about naturally. It's as if I was still living at home, only now I visit them. Because I love them, that's what makes me do what I do.' [13]

The behavioural aspect of affection (love) was described as behaving in a way that shows love to the care recipient by the carer [5,76].

'Taking care of my husband was a way to express my love for him. I needed to express to him that l loved him very much.' [76]

Devotion to care ('*caregiving from the heart'*) was seen as an expression of deep emotional affection (such as love) and as a behavioural aspect of affection, i.e. being devoted to the pursuit of caregiving tasks/role as well as the recipient, not only because of sociocultural expectations but due to affection/love feelings. Devotion was often expressed through descriptions of personal sacrifice rather than words as stated in the second-order constructs [22,33,45,48,57,61,73,76,87].

'I do this role from my heart.' [22]

'I love looking after her I feel I owe her that much and I like doing it . . . it is only what mother deserves and that's it at the end of the day.' [61]

Determination to care is defined as persistence in looking after care recipients no matter how difficult the situation – with a strong emphasis on personal sacrifice. In terms of motivation to provide care it should be understood in terms of maintaining the caregiving behaviour rather than initiating it. Despite the greatest difficulties, many carers made decisions to endure, for some it can be also described as a c*are with sacrifice:* fully devoting to care while disregarding one's own personal comfort and/or security [21,36,40,43,66,68,76,77,90,97].

'You put other things to the way side. That's what loving somebody is.' [21]

'So I will NOT, and I emphasise, I will NOT leave her to go to anywhere. So, I've got her 24/7.' [40]

'All I wanted to do was to take care of him wholeheartedly. I'd continue doing it no matter what happened.' [76]

'I wouldn't consider letting him go away even, however bad he gets... I want him at home and yeah I don't care' [36]

Where provision of care was perceived as a personal choice, motivation to provide care was described as emanating from a personal desire to care. The desire to provide care was connected with empathy (e.g., recognition of a parent in need) and the nature and quality of the pre-morbid relationship with a care recipient (see also the subtheme of relationship quality presented below). Based on the caregiver accounts reviewed we can see that the perception of autonomous choice in providing care was an inherent basis for intrinsic motivation, usually accompanied by affectionate feelings toward the care recipient [17,18,34,42,45,66,79].

'. . . in a fact it's a burden but it's not a burden that I would willingly pass on to anyone else while I can do it. You understand what I mean? I want to care.' [42]

'I didn't hesitate finishing work to look after her. It's something that I want to do and I'm quite happy doing it' [34]

'It's something you want to do for him.' [18]

Feelings of compassion were less often expressed by caregivers as a motivator [25,95]. Compassion was understood as feeling sorry for the other's suffering – for some carers associated with their religious beliefs (caregiving as an act of compassion to alleviate the suffering of the care recipient).

'If you don't have compassion and charity within you then there's no way you can live with them...It's very tiring.' [95]

2.3 Relationship quality

This subtheme describes how the quality of the pre-morbid caregiver-care recipient relationship as well as the quality of actual and current relationship dynamics influence motivations and willingness to provide care [1,2,6,7,9,11,17,23,34,36,39,42,43,45,61,71,72,74,75,98]. In some cases, a harmonious (pre-morbid or current) relationship seem to be a prerequisite for being motivated and willing to care [33], or caregiving itself could be seen as an opportunity to strengthen the relationship and maintain a feelings of couplehood and thus act as a motivating factor [37,40,45,62,70,73,79,97,99] Apart from this a role reversal seems to modify caregiver motivation and willingness to provide care – the examples referring to this are provided at the end of this subtheme content [1,9,26].

Motivations and willingness to provide care were described differently depending on whether the pre-morbid relationship with the care recipient was characterized as close, difficult, distant or positive, negative, reciprocal or non-reciprocal.

The three presented quotations below refer to positive, close relationships:

'I've been his right hand and he's been my left arm . . . . [.] You know, we've been together for so many years and we've done every . . . we thought alike, if we're sitting quiet, and he would say something and I would say, 'Oh I was just thinking that same thing'. [42]

'And Mom was a cute person, huh.' [9]

'I guess I was closest to her…' [7]

The following four presented quotations below refer to negative, distant relationships:

'My mother lived in Japan half of the time. She was just too independent and definitely not an easy-going person. Her children were not close to her. When she got sick, nobody wanted to take care of her. She had to come here.' [23]

'It makes me angry I have to consider him so much when he never considered me.' [71]

'I just, you know, get kind of irate. Because she [mother] never wanted us [children]!' [17]

'She's always moaning no matter what .. .I don't love my mother. I see it [caring] as my duty' [45]

Browne Sehy (1998) suggested that a close relationship may mitigate against negative effects of caregiving and thus increase motivation to provide care. It was noticeable that good communication, sensitivity to each other's needs, a sense of mutual involvement and emotional support in a relationship led to high positive caregiver motivation when a care need arose. The pre-existing relationship quality (i.e. past relationship dynamics) [1,2,6,7,9,11,17,23,34,36,39,42,45,71,72] and the quality of actual dynamics within the relationship, i.e. the strength of the actual bond established between the carer and care recipient were all described as motivating factors [43,61,74,75,98].

'I am the only daughter. I have a very close relationship with my mom. I brought her from China to live with us.' [75]

'We always had a good strong relationship.' [61]

'But there is a closeness there…' [43]

'This is the foundation. No harmony, no elder care.' [33]

Caregiving in the face of a care recipients illness could be an opportunity to strengthen the relationship and there was some evidence that this could act as a motivating factor per se. [37,40,45,62,70,73,79,97,99].

*'More together since ***'s [husband's] had his illness, but before we did do a few things separately, but we enjoy each others company and our interests are almost the same so we enjoy doing things together... I'm with *** all the time now, apart from on the days he goes to day centre.'* [40]

'But I think our relationships have become better. We have talked so very much lately. Before when we came to visit, there were always kids around and so on. We ate and it had been really just busy all the time. Now we just sit there, us two and talk and talk.' [73]

'I think we're a little closer. We're talking more about personal things than we did before. Things we used to take for granted.' [37]

'When I was in my 20s, she called me daily for support in her difficult relationship with my dad. After my mom got dementia, I found that she became more like a "real mom" for me.' [99]

In one Swedish study a carer expressed a strong desire to fulfil their own and the ill person's last wish to remain together (at home) until the care recipient's life ended – this was stated as a strong motivation to continue providing care at home [97].

'She [the ill person] said . . . and . . . extended her hand [almost in tears] and she said like this "X," she said, "the day I die" she said, "I hope that I may die [crying] with my hand in yours."

And she did.' [97]

Role reversal due to increasing care recipient's dependence enforced changes in expectations within a relationship as well and for some carers the ability to adjust to this was an important factor when considering their willingness to care currently and in the future. [1,9,26]. The impact of role reversal may also be highly influenced by gender expectations (described elsewhere as gender-specific roles).

'It's different, it's hard to make that change, the role reversal thing.' [1]

'I think he is, that it is a relationship, I experience it as reversed. I have taken the parental role and I notice that Dad needs this, and somehow he, he wants this help but I do not think he's really – it feels like he is the child.' [9]

'It is like role reversal. It's like I have become the father and he has become the son. It is challenging at times!' [26]

A care recipient's expectations or attitude (a) towards the caregiver and (b) towards the care received emerged as crucial components influencing caregiver motivations and willingness to provide care. Whether the care recipient demonstrated a positive/negative attitude towards the carer (in the form of expressed favour or dislike) or expressed their gratitude or not for the care received, were found to influence caregivers' motivations and willingness to care. The influence of gratitude was clear – it was seen that caregivers felt more motivated if the support they provided was reciprocated or acknowledged, including both verbal and non-verbal acknowledgement [7,17,34,37,38,45,59,73,74].

'It is very hard for me to care for my mother as she is always irritated and annoyed with me. My old sister should care for her but her [the mother's] temper and behaviours made my older sister so worried that she could not control herself.' [59]

'...she and my dad are so appreciative.' [17]

'You know, she always says 'thank you for being here!' Or she goes, 'I appreciate everything that you do!' So whatever bad things happen… she'll tell me that and all bad things go away!' [17]

Another important influence on caregiver motivation was the care recipient's level/extent of dependence on the carer, particularly where the relationship became more asymmetric and demanding [13,36,45,99].

'1 do everything for my dad. Everything. Get him up, shower him, toilet him, dress him, everything because he can't do it himself.' [45]

‘Before, he was so handsome and handy, and now I have to help him with almost everything.’ [99]

The important role played by a care recipient’s level of communicative ability emerged in studies specific to dementia carers. Care recipient’s deterioration in communication skills in some cases seemed to decrease motivations to provide care [13,36,42,45,63,99] with negative changes in care recipient’s communication seeming to result in a caregiver’s reporting a sense of emotional disconnectedness (care recipients were physically present but cognitively or mentally absent) although some caregivers were able to re-establish the loss of spousal relationship due to the emotional disconnectedness and continued providing care against this challenge [13,36,45,99].

‘. . . if I do go bowling and I win . . . say I win the Championship . . . and I come back and I tell her, she doesn’t [respond] . . . there’s no interest, she doesn’t .’ [42]

‘She is very emotional now. Whenever I tried to stop her from doing something she wanted, she would shout at me very loudly. I’m sad but I have to tolerate her. I know that I need some time to accept [this change].’ [63]

Also, relating specifically to dementia caregiving, the issue of the care recipient’s prevailing identity had an influence on shaping willingness to continue caring role. Losing the recipient’s identity due to their illness was found to modify willingness to care. We can distinguish between two situations, firstly where carers were thankful for small preserved traces of the care recipient’s identity/self that helped them provide care.

*‘.. it’s lovely when you wake up in the morning and he says “Hello ***”. Thank God, you know, he knows me… it’s hopeful when, you know, at least he doesn’t wake up and say “Who are you?”. Yeah. (laughs)’* [40]

Secondly where carers perceived a loss of the person that they had had the relationship with – a visible grief expressed by the caregivers over the loss of their recipient’s former identity/self which made it difficult to continue caring [17,36,40,93,94].

‘And that has been the hardest thing for me...all of a sudden, she’s not there anymore...’ [17]

‘My husband is not my husband anymore; I lost my man. At my age of 60, it is like I have a new child. I cannot have the relationship I used to have with him before the illness.’ [94]

2.4 Family values

This subtheme describes familial values expressed in terms of familism, blood relations and the importance of family ties underlying motivations to provide care. Personal and family values were some of the most prominent factors underlying the feelings of duty towards family members in need of care and support and comprised a strong source of motivations to care within the family network. Strong familial values were expressed in terms of familism, blood relations and the importance of family ties with other factors that seem to mediate this influence including the meaning of family and love and satisfaction in family relationships [5,9,13,18,19,22,24,30,48,52,54,55,57,69,92,93,95,99,100]. In the context of family, it was also noticeable that some carers functioned in the role of a kin-keeper, preserving a familial continuity through caregiving [5,14,15,27,28,54,57,66,68,69].

Caregivers may feel obliged to provide care simply because they belong to the same family which is valued by them and society - a feeling of duty related not only to their personal values but also to the values and expectations of the family and society. It could be hypothesised that through this feeling of duty, the caregivers describe how the goal of the action motivates them to care (extrinsic motivation) more than the action itself (intrinsic motivation). These family values were at the core of the constitution of familism: a strong identification with an idea of family [9,13,18,19,24,30,52,54,57,69,92,93,95,99].

‘I do feel that it is in our family values and that when people have it to give they have some obligation to help provide it. Family should be there for family.’ [19]

‘My values hold that one should help one another. ...I may think that it is quite sad when relatives leave all responsibilities to the municipalities.... It has to be the family, I think.’ [52]

‘I learned that's what you do with family. You don't moan and groan about them; you take care of them.’ [87]

‘We are family. We were duty bound to care for mother, and in doing so, we, me and my siblings, had to be loyal to each other. I made myself available to my mother as well as to them.’ [69]

‘We don’t want anybody else to look after our family.’ [18]

Strong familial values and familism are also expressed in terms of blood relations, which in some cases were enhanced culturally (e.g., by norms maintaining high familism) [55,100].

‘She was my mother, I could never have done it for anyone else.’ [55]

‘It is the height of irresponsibility to abandon a blood relation. It is like abandoning yourself.’ [100]

‘Abandoning a blood relation is not done in our culture because blood relationship is very tight.’ [100]

Another example of the influence of family values and familism is seen in how other carer express this importance of family as '*family ties'* [5,22,48].

'*Being Filipino, I want strong family ties, I want to be connected to family.'* [5]

'Love and strong family ties.' [48]

The term kin-keeper was established in social literature by Rosenthal who defined kin-keeping in relation to responsibility for keeping family members in touch with each other [91]. This family role related to taking responsibility for family communications and connectedness; the responsibility for communication in the family and harmonization/continuity of family: forming a unified family around a family member (usually a parent) and facilitating communication and interaction between family members. It seems that some caregivers were taking the responsibility of enabling effective continuity of family also by feeling responsible for the care recipient in the wider context of family, thus fulfilling the role of a 'kin-keeper' [5,14,15,27,28,54,57,66,68,69].

'There always seems to be a family captain in a situation like this and no one else was doing it, so I just did it. I called a family meeting. And I said, if you want me to take the responsibility, fine.' [57]

'My sibling has liver disease. I was the only one caring for him during the harsh treatment periods, and have been taking care of him for six years. I think I became 'the' caregiver within *my family.'* [14]

'Yes, always trying to take care of their emotions. Sometimes my parents will quarrel, then my brother doesn't really understand the situation so he'll create a lot of trouble. I'm the one who have to mediate between everyone.' [15]

'I guess I've always assumed responsibility for the whole family whatever the issue has been.' [28]

Related to one aspect of family values, i.e., the idea how caregivers felt they should treat their family members, was the protection of the dignity and self-esteem of people with care and support needs. For some caregivers, their care provision was motivated by a desire to protect the dignity and self-esteem of the care recipient that was 'assumed' would be lost on entering or receiving various types of formal care or threatened in their local communities or at homes. This shaped initial motivations to care and willingness to continue caring. Treating individuals with respect was an important factor – particularly respect for a parent including exceptional deference and/or courtesy, displaying earnest consideration of them [3,51,54,66,73,86,94].

'We think that the aged have a certain blessing because of their mere chronological age, and

so when you respect and honour them and they bless you, it will be forever on your life. In much the same way, when they curse you, it will also be forever.' [86]

'My husband likes playing cards but he is not able to do it anymore. In spite of this, we still play and I never comment on his mistakes.' [94]

In one study conducted in Sweden amongst the seriously ill [73] the issue of facing their care recipient's eventual euthanasia emerged. Protective instincts were reported as either the desire to keep care recipient's alive and continue to provide care or for euthanasia, seen as an ultimate caring act (releasing a care recipient from their suffering).

'Don't know.. it's a bit scary . . . but I think… would I be able to do it so I would do it.. but it's murder.. but I would have to take it. .then I would have to do it' [73]

2.5 Obligations to provide care

Obligation to provide care refers to the sense of obligations of the individual due to their social role and underlying cultural and/or societal, moral, religious and gender norms shared by the family and/or society. It embraces such terms as the perceived 'obligation', 'duty', 'responsibility' and 'social obligation' toward the care recipient, which are similar to concepts such as 'the duty to provide care', 'feelings of obligation' [13], 'filial responsibility' [7], 'filial duty' [21] and 'sense of obligation' [101] to name just a few [3,7,10,13,14,34,37,41–43,46,47,52,54,57,64,72,87,88,92]. A strong sense of duty to provide care was also described as a 'second nature' or 'natural fact of life', 'opportunity to do one's duty by helping relatives' [17,18,55,61,77,99,102]. Normative responsibility to provide care due to a care recipient's increasing dependency on carers was described by some as being 'forced to take responsibility', i.e. a feeling of being obliged to provide care. It may also refer to the hierarchy of perceived caregiving responsibilities (assessments of who should do what within a family) [1,40,41,87,97,103].

Obligation to provide care related to expectations of appropriate and desired behaviour prescribed by society [1]. It implied a belief in the moral rightness of assuming the caring role, and for this reason it resembled a sense of obligation influenced more by societal expectations rather than by intrinsic motivation [42]. Duty, obligation and responsibility to provide care were typically discerned as an extrinsic motivation to provide care.

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

The actual obligation (1) was referred to as negative obligation, i.e. with caregiving viewed as a duty imposed by social rules and traditions, often described as something caregivers '*have to do'* or that they '*can't walk away from'*. This type of obligation was accompanied either with (a) the (actual) lack of alternatives and/or (b) feelings of guilt [1,17,19,28,34,40,45,46,55,68,70,89], strongly suggesting an extrinsic character to these motives.

Obligation arising from the (a) *the lack of alternatives* but to undertake the caregiving responsibilities (e.g., there is no one else to carry out the care role) was most obvious external motivator in informal care, persistently recalled by caregivers. Many carers suggested that they provide care because somebody had to and nobody else would [1,2,4,6,8–10,15,17,18,21,42,45,55,68,74,78,83,104].

'If I won't do it, no one else will.' [83]

'As a daughter, there's no choice…' [6]

'Since nobody wants to take care I just take care … I got no choice.' [15]

'He doesn't take any responsibility ... It's like being in a trap and there's no way out. I mean to be honest the only escape is when he dies. It's not a very pleasant way of living your life.' [45]

Obligation based on no alternatives could be accompanied by (b) obligation with guilt, i.e. feelings of failing in duty or letting someone down if care is not provided and within this we can see feelings of guilt - the thought of not being able to look after their care recipients was equated with feelings of shame and/or failure, uneasiness and guilt [1,17,19,28,34,40,45,46,55,68,70,89].

'Sometimes I feel like I'm struggling with a guilty conscience.' [28]

'Then I always have to (sigh) be nice in some way ... if I'm away all day and I then want to go out in the evening, I feel as though I'm not being fair to him (sob).' [70]

'She'd make us feel kind of guilty by saying, 'I always took care of my dad'. [1]

'This isn't what I planned to do in the beginning .. .! thought he would've passed away. I sometimes feel guilty about that ..' [45]

Perceived obligation (2) and the subsequent identified variants of this type of obligation (c-g) could be either positive or negative dependent on the perception of choice, whereby this perception of choice was understood as an extent to which the caregiver believed they had autonomy to accept/agree with the potential caregiving responsibility currently or in the future rather than the actual choice determined by the availability of caregiving options. For example, a caregiver could perceive no choice in undertaking and continuing with the role due to their moral and filial beliefs about the obligation (as demonstrated further) even though they had actual choice determined by options of alternative care arrangements such as delegating the duty to other caregivers or a nursing home placement. Thus, perceived obligation was negative with the perception of no choice and positive when the choice was perceived as present. It was clearly noticeable that positive obligation was connected with (and cited along) more intrinsic motives (including for example affectionate emotional involvement; taking responsibility willingly). This resembles to some extent what Statham [45] suggested – that there are two pathways to becoming a caregiver which are shaped by the perception of choice – (i) negative (with the perception of no choice) and (ii) positive pathway (when the choice was perceived as present). Based on the evidence reviewed, we propose that the presence or lack of choice distinguishes between the actual (negative) and real (positive) obligations to provide care. Selected quotes were labelled with letters (i) or (ii) to represent these differences.

'She would be better off if she had a massive heart attack. I often think that. . . . Ideally, that would be the solution, because I would be free.' (i) [13]

'They think the daughter-in-law should take care of the mother-in-law.' (i) [41]

'We are living together, so, I have to take care responsibility' (i) [14]

'Duty had a lot to do with it. She had nobody else. She made me her next of kin without consulting me.' (i) [55]

'No matter how this is, this is my duty.' (i) [77]

''I feel obligated. It's my responsibility. I've been having obligations since I was a kid. They [siblings] all depended on me.' (ii) [72]

'I feel like I am her daughter and I should do for her' (ii) [54]

'It was going to be second nature, I was going to take care of my mother because... And I never thought of because why... It was because that's what I was supposed to do!' (ii) [17]

‘I think that what I am supposed to do. She cared for me when I was growing up. I think what keeps me going is my sense of obligation.’ (ii) [47]

‘I have a responsibility to her, to make sure she is fine. I fully take on that responsibility, to make sure that her life is decent.’ (ii) [103]

‘I think we three children should share the responsibility!’ (i) [41]

Moral beliefs about caregiving as a duty shaped the sense of (c) <u>moral obligation</u> (conscience and moral reasoning, moral principles). It is important to notice that moral motives could still be regarded as grounded in social values informed by cultural systems, e.g., rooted in Confucianism. Nonetheless, we present moral obligation separately to other components of obligation as it referred directly and explicitly to moral considerations in caregiving motivations [9,23,34,49–52,55,68,93].

‘I don't know about the word love, but you do the right thing.’ [55]

‘When you do your part, you'll have nothing to grieve over. You feel sorry, but your conscience is clear.’ [93]

‘I just think it’s the right thing to do. You know, and I think that, that it’s what she wants, and it’s what I want for her.’ [American CG] [50]

‘I do not think too much about the experience (of caregiving) being particularly good or bad. In myself, I feel I just simply do what I have to do. [It’s] a matter of course.’ [Japanese CG] [50]

‘The reason for wanting to do this [referring to wanting to give care] is that you think so… that old people need help. When we are born, we need help, and when we are old, we need help.’ [9]

‘…And also the basic requirements of moral rules.’ [68]

‘I feel a moral obligation towards them and more so because of family tradition.’ [52]

‘My values hold that one should help one another. . . ‘ [52]

‘I feel that as long as a human is living in this world, no matter if they are sick or what, one must live with dignity. She is my mother. How could I see her suffering? I need to help her feel comfortable.’ [23]

It was consistently noted that (d) <u>filial obligation</u>, duty or responsibility signalled a strong separate code with adult-child caregivers influenced by Asian ideology of filial piety (or filial respect) – caregiving perceived as an obligation, therefore a strong motivation for caregiving. It seems that for carers ‘filial piety’ was synonymous to the perceived obligation towards parents. Cultural values underly the sense of filial piety towards parents (i.e., traditional value of filial piety). The symbols of filial piety included and were not limited to: respect, repayment, taking care of parents at home, and not sending parents to nursing homes. Interestingly, even those participants who providing or receiving spousal care (not adult children) consistently conceptualized informal care as something that ought to be provided by adult children due to filial piety – the last two quotes below are provided as examples [5,8,15,23–25,27,29–31,33,35,41,68,75,77,78,88,95,98,105].

‘All of us are human. If we are capable of doing, we do our best. I help people even though they are not related to me. For my mother-in-law I should do more.’ [98]

‘It is my duty to take care of them.’ [5]

‘I have the opportunity to care for my dad, and I talked to him that caring for him was my honor to repay him because I’m able to do it. I’m unashamed.’ [41]

‘I’m really grateful that she passed away at that age without making much trouble, but still, it was not easy for us. As the oldest son and his wife, we have the responsibility. It’s because even if other children don’t care much, we should take care of them until the very end.’ [78]

‘The most important reason (to provide care) is familial affection (with my mother) . . . to show my gratitude for what she has given to me, to fulfill the obligation.’ [68]

‘I must take care of my mother. I cannot say no. This is my obligation and I cannot say no. Otherwise, what kind of woman am I? That is unfilial.’ [77]

‘It is natural for Vietnamese to love and to feel obligated to take care of parents. I don’t want my parents to feel lonely, especially when they are in another land.’[3]

‘Let’s still do it our old ways. At the very least, children should be filial. Elder care should be up to the standard of filial piety.’ (man provided with care by his wife) [33]

‘If the children are filial, they won’t get the parents mad. They would know that it’s not easy to live to old age.’ (spousal carer) [33]

The sense of (d) filial obligation and responsibility was paramount in studies and is not only constrained to the underlying cultural value of filial piety [1,3,5,9,11,12,14–16,19–21,27,49,57,66,79,85,87,94,106].

‘I am his daughter.’ [16]

‘ I care for her because she’s my mother.’ [3]

‘I am taking care of my mother because she is my mother. Who else can do this? This is my obligation.’ [3]

‘Well, you cannot just leave him, then he’d just be sitting there. Nope, but, it's well… the feeling you have that you need to help him.’ [9]

‘Well, I think like this. He's my dad in any case (laughter).’ [9]

‘But somebody has to do it and I feel then that I should do it. I have to do it; it’s as simple as that.’ [9]

‘Why? Because she is my mother and it comes naturally.’ [19]

‘[My mother] told me, ‘If you never look after me I also don’t know who looks after me.’ I as a daughter what to do? I need to look after you.’ [15]

‘You do what you have to do.’ [57]

‘I have a responsibility to my father, and I think we all have responsibilities to one another. I guess I am being as responsible as I can in a bad situation.’ [57]

‘I kept telling my husband, let’s do what we can. I feel it is my responsibility. I just ought to do it.’ [5]

‘It’s my task as a daughter.’ [106]

‘Well, I think because we are their children, we have to take responsibility for them. Like they gave their lives for us and all, brought us up as children.’ [79]

A sense of (e) spousal obligation to provide care, the extent to which carers felt they ‘*had to*’ or ‘*needed to’* perform tasks for their partner, may be largely attributed to strong influences of cultural/societal values and beliefs described as ‘*loyalty*’ or ‘*obligation’* or ‘*commitment’* arising from (long-term) marriages or partnerships. Marriages themselves were reported as reason for informal caregiving, suggesting an acknowledgment of both the internal psychological factors (e.g., moral considerations) and societal model of expectations and entitlements within marriage/partnership relations [16–18,26,28,30,31,38,41,42,45,55,56,59,60,64,68–70,74,77,82,90,94,107]. Although a sense of spousal obligation may be reported all over the world, one Korean study [31] included carers who stated they have lived with their husband under the same roof with no feelings of love or affections due to an arranged marriage where they maintained their married life within the Korean traditional social code. This is in contrast with the more common perspective of spousal obligation being connected with emotional attachments with the care recipient (intrinsic motivation) - an obligation (detached from marriage) and a love act coherent with ties made by a couple married for life [18,64,94].

‘I think that when you’ve lived together and had such a good life, you have to be there for your spouse.’ [28]

‘I feel glad to be able to serve my husband this way... it is my obligation...’ [107]

‘My husband... I have to take care of him. If I don't, who will?’ [107]

‘The main person to take care has to be us. We are married, we have our husband, we have to watch over him.’ [74]

‘I am married to her, and I still take that very seriously. When you give your marriage vows, and marriage is forever, forever and a day, well, stick to them.’ [38]

‘We've been married 50 years so naturally you take care.’ [55]

‘It’s your husband, you’ve been married to him a long time, it’s in your marriage vows, it’s something you want to do for him.’ [18]

‘This [caregiving] is my obligation . . . I cannot leave him [husband] when he is ill. That is, I cannot do it [leaving her husband] according to my conscience . . . There is a voice (in my head). Someone (in my head) was telling me that ‘you cannot leave. No matter how hard it is, no matter how bad you feel, you have to stay.’ . . . I was only doing what I should do as husband and wife. No other reason.’ [68]

In some cases, the desire to maintain a marital relationship by taking care of a spouse’s relative in need was seen to motivate care. For example, Globerman’s [82] study of caregiving daughters- and sons-in-law describes a female caregiver who provided care in order to protect or manage her husband’s suffering in relation to coping with his own parents illness [82].

[daughter-in-law] ‘My involvement with my mother-in- law has been not really helping my mother-in-law but actually helping my husband.’ [82]

[son-in-law] ‘I do as little as possible. If it has to get done, I'll do it. I don't go out of my way to look for work to do. My wife does the bulk of it because she's taken on the maternal role.’ [82].

Extended familial obligation (f) refers to the situation in which different family members (carers) felt responsible for supporting the family unit, often influenced by affective ties or a close kin relationship. In some studies an entire family was expected (culturally) to be to be involved in caring for the recipient [11,17,32,84,85,100].

‘Our elders are always taken care of—cancer or not. We do not need to designate a family caregiver, as everyone chips in to ensure care is provided.’ (Hawaii) [11]

‘I just help my family. I think it is right to help other people.’ (KwaZulu-Natal, South Africa) [32]

‘I don’t have any problem with [caring for the child] because I know that he is my child’s, so he is mine too.’ (KwaZulu-Natal, South Africa) [32]

‘If a family does not care for her member living with HIV/AIDS, nobody will.’ (Nigeria) [100]

‘Marriage in this area is between two families and not two individuals. This makes the marriage stronger and makes it almost impossible for any of the two persons to opt out of the marriage because so many people are interested in the marriage and none of the couple may want to disappoint the people. In fact marriage in this area continues even after the death of a spouse.’ (Nigeria) [100]

‘We had a sibling meeting. And we all went around the table telling her why we wanted her to stay at our house.’ (Hispanic American carer, Texas, USA) [17]

‘There are four more younger siblings in Canada–If I can’t take care of her over here, they will come here illegally to take care of her.’ (Vietnamese American carer, USA) [84]

The notion of (g) collective obligation means that the individual is a part of community relationships and is obliged to fulfil their obligations to the collective community (rather than familial relationships only). Examples from the African cultural context demonstrated cases where the entire community regarded every child as their child and in this collective ownership of children, the society meets obligations to all children; the same applies to adult children helping older members of their community. Another example revealed an implicit understanding that people have to care for their parents and family as embodied in the concept of Ubuntu (understood as ‘*brotherhood or sisterhood*’) – implying togetherness, helping each other, caring for each other or more generally ‘humanity’. The traditional care arrangements are such that it is the community and the family that care for the person with care needs [44,100,108].

‘How can I be happy when my brothers and sisters (neighbours) *next door are dying; are hungry; are sick? It is my duty to help; to care; and to feed.’* [44]

‘In this area, a child belongs to the immediate family, extended family and the community. As such, training and caring for a child is seen as the responsibility of everybody in the

community. When the child is sick, the entire family and community rally round to nurse that person. It is actually a shame on the family for their sick relation not to be taken care of and no family likes it.' [100]

Theme 3: Personal characteristics, beliefs and resources

This analytic theme describes the individual caregiver characteristics, the caregiver beliefs and the perceived or actual resources which contributed to motivations for assuming, and maintaining, the caregiving role. The theme incorporates five descriptive subthemes: caregiver's personal characteristics and inner resources (e.g., being intelligent, organised); caregiving experience and expertise; coping responses; finding meaning; seeing care recipient's illness.

3.1 Caregiver's personal characteristics and resources

This theme concerns personal characteristics (such as carer age or health status) and inner resources (such as being intelligent, knowledgeable, helpful, patient, assertive, skilled, organized, quick, active, easy going, logical, confident, conscientious and strong), including caregivers' belief in natural affinity for caregiving (which could be discerned as a personality trait – being a caring person). Inner resources have been defined as personal factors that support the caregiver in effective coping with caregiving demands, attaining goals, and achieving personal growth and development [109,110]. Inner resources are developed out of discovering one's identity, striving for wholeness and a sense of empowerment [111,112]. Some carers recognized it was natural for them to be caring (in different ways, including caring nature) even before the caregiving commenced [7,18,25,43,74,79].

'That's just the way I am, I guess. I don't know. I just take care of her.' [79]

'. . . one isn't taught that, my girl, that [ability] comes from your heart, you will never learn that, I tell you that from experience and from my 66 years, no one will teach you to care for [or] love people, [it's up to] you alone.' [79]

'Well it is just that it has probably always been natural. When I have felt that I can help someone, I try to do it. And this applies not only to them [his mother and aunt], it applies to my friends, it applies to my children.' [9]

'It's probably something I've had in me all my life basically. Like to help others. It feels good somehow.' [9]

Dispositional optimism was also noticeable in studies reviewed and included: a hope for a miracle to happen; holding hope and good things in life as of great importance for caregivers to continue their role [13,68,73,76,94]. This was strongly linked to positive motivations to continue with providing care.

'I don't know, hope. I've always thought that he would get better, that he was going to be all right. . . and you try, and you try.' [13]

'I am fortunate with my husband. The mother of a friend of mine has Alzheimer's, and she is much worse than my husband is. She is bedridden and has plenty of [decubiti]. I hope this never happens to my husband.' [94]

Other personal characteristics mentioned in relation to motivations and willingness to provide care included the caregivers' own health, their age, having children (as raising the sense of responsibility and means of obtaining support) and having the physical ability or health to deal with caregiving demands [20,34,46].

'...you look back and you see, particularly when you have your own kids, and you understand that aspect of the responsibility more.' [46]

Personal characteristics may also define the lack of perceived affinity towards the caregiving role.

'It [caregiving] was against me' [43]

One elderly caregiver referred directly to their age [20].

'When you live to my age, there are many inconveniences. [...] But if my mum wants me to do something for her, if I am able to do that, I'll do it.' [80-year-old caregiver] [20]

3.2 Caregiving experience and expertise/competence

This subtheme refers to the previous caregiving experiences and the sense of competence and skills in the role which were found to play an important role in how willingness (and also ability) to provide care was experienced [28,54]. Having experience of caregiving roles and having gained competence and skills such as an ability to manage challenging behaviours, was seen to have created a feeling of security, resilience or confidence in their caregiving role [14,37,69,103].

'She [CR, mum] took care of... And then when I was 12 my father had a stroke, I remember I taught him alphabet [...] I'm used to giving care.' [54]

'It's important to be competent in nursing. I'm sure it is much harder for an untrained person to take care of an elderly. I know the body's mechanics. It was still very challenging for me to care for her.' [69]

Likewise, having personal experience in dealing with or managing illness and death was sometimes reported as a motivator to provide the current care [44].

'I lost my sister and brother to HIV. I want to help other families so that they can handle this pain when it is their turn.' [44]

For one African caregiver, their hope of becoming a professional caregiver in the future was motivating their informal care and taking part in a training helping with caregiving [44].

'*I am unemployed. By volunteering, I can keep busy. Maybe I will be lucky and the COC [Community Outreach Centre] will employ me as they have done with my other colleagues.'* [44]

'I expect COC to train me so that I can give better care to my patients. I expect to get employment, especially with the good training COC gives me.' [44]

3.3 Caregiver coping responses

Coping refers to the different ways (cognitive, emotional, behavioural) caregivers respond to their caregiving situation and the challenges it can present. In the reviewed evidence, coping strategies played an important role in maintaining (or not) the role rather than initial decisions to provide care, i.e., the way caregivers coped with their *current* situation influenced mainly their motivations and willingness to continue to provide care. Caregiving motivations and willingness also fed back bidirectionally to caregivers' coping responses. The range of coping strategies indicated by caregivers reflected the dynamic and contextual nature of appraisals, the caregiving context, and the perceived and/or actual availability and effectiveness of formal and informal support [34].

Several taxonomies defining coping and the dimensions therein exist [e.g., 147,148], yet here we present caregiver situational coping responses which emerged from the inductive synthesis of the data by grouping them into two categories: 'Facing a stressor' and 'Avoiding a stressor'. Under each of these categories, specific coping strategies and their relation to motivations are described. The reviewed data is then presented in terms of approach- versus avoidance-oriented coping categories. The approach-avoidance conceptualisations are not considered as unidimensional and within each category separate coping strategies are described. Moreover, approach- and avoidance-oriented coping are each represented by cognitive, emotional and action-oriented strategies, a summary of which (axial codes) is presented in Table 1 (see below).

Table 1 The summary of coping strategies in relation to theoretical approach- and avoidance-oriented coping dimension.

Domain	**'Facing a stressor'** **(approach-oriented coping)**	**'Avoiding a stressor'** **(avoidant-oriented coping)**
Cognitive-emotional	Being grateful for the current situation (positive reframing)	Using humour (as a defensive strategy)
	Taking control and accepting the situation	Viewing care recipient's anticipated death as a rescuer
Emotional-social	Attending one's own needs	Seeking social isolation
	Using available family support - Sharing caregiving duties with family	
	Seeking formal social support - Attending support groups - Seeking connectedness with other caregivers - Using professional help	
	Engaging in religious practices as means of emotional and social support	
Action-related	Preparing for caregiving (Planning)	Distracting oneself through focusing on caregiving personal care tasks
	Using respite care support	
	Having 'me' time	
	Using formal home care services	

'Facing a stressor' (related to *the approach-oriented coping category)* refers to individual strategies which deal with life active approaching of the stressor, for instance by planning activities, using social support, attempting to solve the problems. 'Avoiding a stressor' (related to *the avoidant-oriented coping category)* relates to either a passive or disengaged way of relating to stressors/stressful events or an active aspect away from the stressor, including for example denial, diversion or escape.

'Facing a stressor' (approach-oriented coping)

The first dimension of 'facing a stressor' is related to **approach-oriented *cognitive coping*** domain and refers to strategies reflected by caregivers which involved a positive reframing (below) and acceptance of the current situation (below).

Feeling grateful for the nature of the caregiving situation by making comparisons between possible health conditions that a care recipient could be in (i.e. i.e. with other, worse, health conditions that their care recipient could have) was mentioned in one study in relation to motivations to provide care [40].

'Suppose I should be thankful cos as I say it's gonna get far worse.' [40]

Accepting the role and developing a routine in which the care recipient plays a more important role than they had been previous to the illness helped the carer to adjust to their role. This may also influence willingness to provide care [38]. Daily routines, where it was possible to put in place, were experienced as reassuring, providing structure to life – offering a sense of control in otherwise uncontrollable circumstances. Some caregivers considered that their role became easier over time due to the care duties becoming habitual – acceptance enabling the establishment of 'the new normal' and a shift in priorities and goals [18,19,28,38,40,51,68,73,89,99,108].

'You get used to it and, in the end, well, you have a totally different life which is bound to home and to her.' [38]

'I guess we have both sort of adapted… I am not sure my expectations changed as much as going along with what is inevitable.' [19]

'It is difficult but I have got used to it.' [108]

The second dimension of 'facing a stressor' referred to **approach-oriented *emotional-social coping*** describes mainly seeking and using informal and formal social support. For some carers the focus is on one's own emotions and needs, for example, realising the imbalance between caring demands and personal needs an attitude to protect oneself through giving attention to one's own need as well was seen [73].

'At the same time I don't want to completely lose myself, no I don't.' [73]

Social-emotional coping is seen in *informal social (emotional or practical) support seeking behaviour*, with the availability of family support playing an important role in shaping initial and continuation caregiving motivations and willingness to provide care. Social support could differently affect caregiver coping depending on whether family support was available (the presence of sibling network / family network) or lacking. Where available carers avail themselves of family resources and receive direct help from family members in providing care and/or help via the handling of other tasks including caring tasks, tasks not associated with the caring and financial assistance. Family support was recognized as being fundamental to provide care by many carers - for some it was a key factor that enabled them to provide care for a care recipient at all; it was an important factor in whether many caregivers experienced caregiving as positive. In some cases, a decision to become the main caregiver in the first place had been based on the availability of other family support, and for some it influenced whether they felt able and willing to continue care [1,2,5,9,13,18,20,26,29,34,42,48,57,59,61,64,68,77,78,88,91,93].

'[I receive] assistance from my daughter.. it's mostly the ones in my household that help' [48]

'We got lots of emotional support from family, even the ones that aren't here.' [1]

Some caregivers expressed negative feelings about the lack of support from other family members [2,18,29,57,61,91] due to, for example, poor relationship quality, relatives' differing or competing priorities, social geography/distance. Such factors meant some carers feel unable or unwilling to ask their family for help. Having this support made the caregiving role easier, thus its lack was negatively reflected in motivation to continue care. The findings of one study [18] did reveal that some caregivers accepted the lack of family support as part of modern living.

*'To get everyone to sit down and talk about it [*caregiving*] is impossible . . . it is as if there is a sense of fear with some of them that they just don't want to hear.'* [61]

'They aren't willing to help. I get tired of asking for help...' [2]

For some, caregiving was performed as a coordinated team effort within a household or whole family. Coping by means of family care sharing (e.g. between siblings) and/or through rotating duties was found helpful and motivating [2,17,48,69,88,99]. The studies included, however, did not relate this issue to relationship quality and shared understanding of one another's roles and responsiblities.

'If I didn't have so many sisters, I wouldn't be able to do this!' [2]

'I make sure others help, and they listen. This is the way it has to done' [2]

Family support also acts as a means of socializing which for some carers provided links to their '*normal life'* [21,42,88,93,99,106,107], which was understood as a life alongside caregiving.

'If I need to vent, I go to my friends.' [21]

Finally, approach-oriented emotional coping strategies related to the *use of formal social support*, with organized carer groups being reported as a mainly positive source of support. [42,88,90].

‘Going to these support groups, I found it so incredibly helpful for me, just because to hear about other people.’ [88]

Formal support groups elicited feelings of connectedness with other caregivers, people in a similar situation, and this could help carers to reframe their situation, reducing the perception that they are the only ones in such a situation [68].

‘When you look around, you can see many other people just like you . . .The family caregivers, we also belong to a group.’ [68]

Some caregivers were appreciative of the formal services, which reduced their burden and enabled coping - many felt more secure knowing that the health and social care system (particularly home care nursing assistance) would be there to support them if needed [37,72,78]. It should be acknowledged that sources of help and support, the ways these are organised and delivered, vary across countries, therefore influencing these findings.

‘The nurse was so caring that there were no bedsores any more. According to the nurse, my mom had the worst bedsores she’d ever seen. Strangely, she got cured in just three or four months. I’m so grateful to the hospital because they assigned nurses who specialized in bedsores in each region and sent them to our home to treat patients in person.’ [78]

Drawing on one’s religiosity or spirituality as a coping strategy, religion was predominantly expressed as central in caregivers’ lives with spirituality and prayer as the most commonly used coping strategies (see Part 1 – subtheme 1.3). Drawing support from one’s religious beliefs was thought to have helped in overcoming some of the frustrations and stresses associated with care responsibilities and contributed to how the caregivers coped with these. Drawing on one’s faith/religious or spiritual support can be considered as a personal resource and a source of emotional social support (e.g., ‘*So at church, you get the support from the people, the church’*) [5,26,39,42,47–49,54,63,77,88,89,93,95,98,100,107].

‘I just put my trust in the good Lord, and He'll give you strength.’ [93]

‘You’ve got to do a lot of praying. It’s the only thing that keeps me strong...to help take care of her.’ [48]

‘God gave me strength to do it [caregiving].’ [54]

The third dimension of ‘facing a potential stressor’ referred to **the approach-oriented *action-related coping***, i.e. planning and actively tackling the caregiving responsibilities through the usage of instrumental formal support (e.g., home care services, respite care services) and the ability to have breaks from caregiving.

Preparing for caregiving through thinking about it and planning for the future (e.g., care plans where professionals were involved in care planning) was helpful in sustaining motivations for caring [40] although it should be noted that not all caregivers have this possibility.

‘Um, I suppose I’m willing really to do it, yeah. I am expecting it, I mean I don’t really know what to expect, but all I can see, everything you see and read, you think “Well it’s got to get harder” I would imagine, unless they suddenly get some miraculous breakthrough with, with something.’ [40]

Where caregivers had an opportunity to take advantage of respite care services, the temporary alleviation of the caregiver burden caused an increase in subsequent motivation. This may have been achieved through respite enabling caregivers: to meet their own basic needs such as nutrition or sleep; to improve in the structure of everyday life; to provide more variation in personal activity [65,89,93,99]. Interestingly, the evidence did not provide the negative implications the respite care services may entail as evidenced in a scoping review [115] which higlighted that respite care can also heighten carers sense of guilt or anxiety.

‘The day care means a lot. It gives me at least two days a week to do what I want. I can pay some attention to my own needs as I usually use all my time to attend to his needs.’ [89]

Having 'me' time, i.e. the ability to have breaks from caregiving (as a result of informal help provided by relatives or friends or the availability of such arrangements with the care recipient), worked a catalyst for subsequent coping with caring duties [40]. Trying to maintain the sense of balance due to the demands of the role (as contrasted with the demands of other roles, e.g., of a wife or parent) through engaging in personal leisure activities [107].

‘Interviewer: Do you think that’s helpful for you to have the time?
Carer 6: Yeah, yeah cos it do, although as I say we get on alright, it’s just nice for me just to have a little, do what I wanna do without thinking “Oh well”.’ [40]

‘I enjoy taking care of my garden and watching the flowers and the herbs grow. It makes me happy to see it every morning when I wake up.’ [107]

Home support services (e.g., a provision of basic home management, cleaning or household assistance as well as community nursing care) were viewed as a lifeline for some carers, with the additional time for themselves it offered contributing to higher motivation and willingness to continue caring [48,61,91,97]. The terminology, though, differ across countries, e.g., in the UK the term ‘home care services’ is more common.

‘I’ve been taking care of my mama for 10 years, but if it hadn’t been for adult care I would have put her in a [nursing] home one year ago.’ [48]

'It allows you a sense of relief and freedom from the caring role so you can relax. If there was not the support there you could not cope full time without services . . . you would not be able to do anything . . . you could not cope.' [61]

One caregiver, however, did not feel that home help was a secure option [97]. Other negative correlates of home help such as problems with the organisation, reliability and flexibility of provision increasing a caregiver sense of burden were not mentioned in the reviewed literature.

'I'm secure when I know that he is there [with the children]. But I wouldn't feel secure leaving him with an unknown person or a home help.' [97]

'Avoiding a stressor' (avoidance-oriented coping)

The first dimension of 'avoiding a stressor' is realated to **the avoidance-oriented *cognitive-emotional coping*** and refers to the use of humour (as a defensive strategy) and cognitive distraction/diversion. The use of humour was common [37,45,89], reported by carers to help them continue with caregiving on daily basis by making light of aspects of their situation. It should be noted that the use of humour appeared as a defensive measure in caregivers' accounts, i.e. humour found in stressful situation (e.g., care recipient's demanding illness symptoms) reduced negative emotional reactions what - to the great extent - was related to defensive mechanisms such as minimisation and reversal [e.g., 112,113]. Caregivers using these strategies seemed to be more willing to provide care compared to caregivers using the remaining two avoidant-oriented coping strategies (emotional-social and action-related ones).

'We [my children and I] have fun. We laugh. The things that come out of my husband because of his receptive aphasia are so funny.' [37]

Care recipient's anticipated death could also be seen as a rescuer from significant caring responsibility. In one study the thought about the possible ending of caregiving seen in the recipient's death was cited as (a second-order construct) one of the factors influencing continuation motivation to provide informal care [70].

The second dimension of 'avoiding a stressor' encompasses **the avoidance-oriented *socio-emotive coping*** and refers to caregiver social isolation. In some circumstances (e.g., caregiver's embarrassed by the care recipient's illness), carers not only felt isolated but they even chose this isolation (i.e. constraining their own social life and relationships with other people) based on their perceived caregiving situation. This, in turn, was negatively reflected in their continuous motivation for caring as isolation was experienced both as desired and painful [15,28,37,61,68,76].

'Your social life and your work have to stop . . . even relationships . .' [61]

'I'm finding friends that we've known for a long time, they don't come [visit]. They don't phone. They don't know how to react. They don't know what to say when they come [over].' [37]

Finally, the third coping response refers to **the avoidance-oriented *action-related coping*** domain, which focuses on an example of action distraction – through engaging oneself in caregiving work. Actively coping by taking action in dealing with caregiving tasks (i.e. focusing instrumentally on the caring tasks) in order to ameliorate the situation and reduce the existing demands which may not be pleasant [61]. It enabled dealing with caregiving effectively but with important constraints: engaging oneself in instrumental caregiving work may have been efficient in a short-term perspective but in the long run it could lead to burn out and had adverse effects on continuous motivation and willingness for caring.

'I look on it as a job that has to be done. I am not emotional or embarrassed . . . it is not always pleasant emotionally or otherwise.' [61]

3.4 Finding meaning

Finding meaning as a subtheme related to cognitive (a way of making sense of caregiver experiences); emotional (carer satisfaction and fulfilment) and existential (making a choice in caregiving and the issue of responsibility) components of caregiving. Finding meaning and meaning making have a motivational component, either understood as the reason behind caring or as a way that helps motivate the carer to sustain coping.

It is worth noting that the concepts of 'finding meaning' or 'meaning making' have been interpreted in different ways in research literature [36]. Some consider 'meaning' in two dimensions, i.e. a cognitive one which pertains to beliefs held about caregiving experience, and an emotional one which relates to satisfaction with the caregiving role [118]. Similarly, it is also discerned as two separate processes of searching for meaning (attempting to make sense of the caregiving situation) and finding meaning (experiencing the caregiving as meaningful) [118,119]. With respect to the latter component, finding meaning was often interpreted as reflecting the positive aspects of caregiving [120,121], e.g., gaining satisfaction through acting on personal values or beliefs. There are those who understand finding meaning as part of the coping process [122] in which 'meaning' is a mediator of the stress process. Pearlin [122] conceptualised 'meaning' as a mechanism involving the reduction of expectations, the use of positive comparisons and a search for a larger sense of the illness. There are also those for whom finding meaning is part of existential discourse [119,123] highlighting that meaning is found through making choices or emergent from searching for a provisional (day-to-day sense of purpose) or ultimate (spiritual/philosophical) meaning [124].

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

Caregivers make meaning of their caring experiences (retrospectively) and the reflection accompanying this was seen to be a powerful factor in motivations to provide and continue to do so. These cognitive interpretations related to the beliefs (about what has already occurred) that carers held about their caregiving experience [9,21,25,57,63,65,68,73,97,102].

'After being in this for a while, you start thinking what is the purpose [in life], and maybe the purpose is giving instead of getting. And so you give in some small way to somebody else who's important to you.' [57]

'As a teacher you're always amazed and pleased to see your students grow. One day I woke up and realized how much I had grown and how much more I valued my life and ours together. I never felt the growth.' [102]

'But I think it has a bit to do with me getting help to deal with my own fear of death, that I definitely have got . . . we're all going to die but he's so calm about it all.' [73]

'This is my chance to make up for all that. I've had a lot of time to think about this stuff in the last seven years and . . . and I've changed a lot, you know? We lost everything as far as money, but . . . ah . . . ah, I feel better about myself now than I ever have . . . I guess I've found a new kind of love for our life together. . . (long pause) . . . damn, this is hard to explain.' [65]

Some carers expressed how caring brought a new perspective on living, which is felt to be fuller, truer, authentic – often in relation to the awareness of the shortness of life as a direct reflection due to care recipient's health condition. The realisation became clear and tangible over time [28,97].

'You learn to appreciate life more . . . We're not counting on doing things when we retire, we're doing everything now. When you get to be 65, you might have problems with a bad knee or with heart-failure. So it's probably the case that this has increased our quality of life.' [28]

'And think when I'll die," she said. "Yes," I said, "we don't talk about that. I don't think that far ahead," I said . . . We'll not think about it now, for we'll live in the present, that's that. She took it up many times.' [97]

The importance of good memories as a motivating factor, finding meaning in what is past, was also visible in the caregiver accounts [28,92].

'I mean, it gives you some perspective regarding life. After we retired, we travelled to Spain every year, and we had a nice summer cottage in the archipelago. We had many fine years together. We felt fulfilled.' [28]

‘The most satisfying times we have now are when we talk about the past.’ [92]

The emotional component of finding meaning referred to the feelings of personal satisfaction or happiness derived from having helped the care recipient, described by some as ‘being happy from within’. Moreover, caregivers who felt that caregiving was consistent with their personal values felt most adapted and comfortable with their role, with an evident sense of finding meaning [14,15,17,44].

‘It makes me happy and satisfied to help others; I want to give something back to our people and community.’ [44]

‘...the inner gratification that comes with that, you can’t measure, you just can’t measure.’ [17]

Caregiving was also perceived as an opportunity for self-growth [7,25,73].

‘I am not afraid. . . . I feel that was my blessing, even though there were many hardships. Living with parents when they are alive, having the opportunity to take care of them, that is a great blessing. . .’ [25]

‘I’ve probably become stronger, you get some kind of strength, like nobody is going to boss me about…’ [73]

Gaining a sense of purpose for living was seen in the data in two ways. Firstly, the act of caregiving gave meaning to the carer’s life and comprised the main reason for caring and living, with terms such as ‘*vocation*’, ‘*calling*’, ‘*purpose*’, ‘*mission*’, '*engulfed*' being used to describe their experience. Notably, such feelings extended beyond motivations to care as it was considered as providing a main and general purpose for living. However, in the case of death of the care recipient life may have suddenly lost its meaning suggesting that this influenced caregiver adjustment to their bereavement. On the other hand purpose for living was also discerned as coherence with caregivers’ life purpose without the perception of caring as the main and general aim for living [5,13,34,45,47,52,60,76,97].

‘At [from] the beginning I feel I have a mission.’ [5]

‘I am truly, truly convinced that my purpose in life as of now is to provide love and care for my sister, so it is no big deal for me.’ [47]

‘That’s why I’m, er, wanting him [her husband] alive for – me – really aren’t I?. . .to have somebody to go and see’. [34]

A reason to reconnect in often difficult or complicated relationships with a care recipient (e.g., a caregiving son trying to re-connect with his ill father) may be the source of motivation to provide care. A sense of wanting to make up for lost time, including learning why their parent had once abandoned them or getting new attention and building a connection they never had as children – all these served a purpose of finding a new meaning in a relationship where caregiving became an opportunity for these. It is not only constrained to adult children carers, as one spousal caregiver also expressed a similar view [9,68,89]. This is complementary and linking view to the subtheme of the relationship quality, described earlier.

'But I think I do it because I did not have the time to be with my mother when I was little, I think. I do not know.' [9]

'I'll say this – he might not have been the world's best dad, but he was my dad. And I've always looked up to him. And I do not think he has understood this because I think he's a lot like me. I'm not very impressed with the kids today. I do not think he was either at the time. I [my birth] was probably more something that just happened, that he had not counted on, and being on the road it was too much. And then he probably had a bad conscience when he sailed to America when I was a kid of this size.' [9]

'While I took care of him, he began to care about me for some time. He had never cared for me before. Now he knew that I was tired and it was hard for me. He was able to think about me. I was touched.' [68]

3.5 Seeing care recipient's illness

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

Personal illness perceptions emerging from the reviewed findings referred to either individual beliefs about the attributions of cause of the care recipient's illness [34,50,63,84,95,100], or the perceived severity of this illness [36,97] or the perceived lack of purpose of the illness [9,28]. However, based on the fragmentary and complex nature of illness perceptions reported, it is difficult to discern the exact consequences they may have brought about for motivations and willingness to provide care – some hypotheses, based on understanding of the literature are presented in the text.

Different attributions of cause regarding the care recipient's illness were reported: normal ageing process, physiological factors (e.g. a diet), psychosocial factors (e.g., '*It only happens to people who do not know how to take care of their minds*.') and spiritual ones (e.g., the spirit possessed the recipient and caused the illness) [34,50,63,84,95,100]. More specific causes included: recipient's illness as the manifestation of God's will or plan [95]; demonic possessions, curses, or spiritual possessions as causes for dementia [95]; lack of belief in early-onset dementia [63]. Cultural differences in perceptions of illness and ageing were discerned, for example being old was treated as natural part of life (e.g., '*Forgetting is normal in Vietnam, it is not really a disease'*) contrasted with cultures where the issue of death is a kind of taboo subject [84]. We hypothesise that in the first case caregiving might have been anticipated and thus accommodated and prepared for (although not in case of acute episodes, e.g., strokes). In the case of cultures where death and ageing comprise more of a taboo topic, caregiving seemed to be more unexpected, resulting in lower readiness to accept their care recipients' illness [50]. Based on the content of attributions caregivers spoke differently about their willingness for caring. For example, if an illness was understood as a care recipient's own fault (e.g., God's punishment), then caregivers seemed to be less willing to provide care in the first place. On the contrary, if the illness was discerned as a natural process of living, the caregivers were more accepting of the role and treated the caring as an expected part of life that should be undertaken.

'Forgetting is normal in Vietnam, it is not really a disease; it is very normal.' [84]

'In the old days we ate too much fat, it stayed in the brain blood vessel, then ate too much salt that caused high blood pressure.' [84]

'It only happens to people who do not know how to take care of their minds.' [84]

'My partial understanding is that in Vietnam this woman (his wife) was rich and well-off, so the spirit took over/possessed her and caused her to be in pain and ill. She is taken over/possessed by this thing and that thing.' [84]

'God gave humans that, so it just has to be like that. There's nothing we have to be afraid of.' [95]

'This is because it is believed that a strange illness is punishment from the gods.' [100]

'I can't believe that he is demented. He is in his 50s. He is still young. Why him?' [63]

'But gradually, I began to feel, "Oh, well, this must be a law of nature [shizen no setsuri; laugh]." You know, like dying tree gradually changes, her body (also changes), you know, she is 89. I have come to feel that it cannot be helped [shikatanai], that gradually many functions deteriorate over time.' [Japanese CG] [50]

'It's just—I think it's something we don't ever prepare for. It's something we get thrown into.' [American CG] [50]

Another aspect of caregiver's illness perceptions refers to the severity of a care recipient's illness and caregivers' responses to them which were found to influence motivations to provide care. Caregivers found it difficult to see the illness 'breaking down' the care recipient and this was noted as the reason for deciding to place the care recipient in a nursing home [36,97], i.e. motivation to discontinue caring.

'I see how he is suffering. And it affects me too; psychologically . . . He is probably scared [whispering] at the same time . . . He is always saying that he wants to die. I really understand

that it is . . . ebbing now. So I'm conscious of that, obviously.' [97]

Two studies mentioned the issue of the lack of purpose in the care recipient's illness. The carers strongly expressed the view that there was no meaning found in the care recipient being ill [9,28].

'I must say, sometimes I've had a little praise. But meaningful? There's nothing meaningful about a serious ill-ness. It would have been better without [the illness]. And then to go there when they need help – it's not like having quality time together.' [9]

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A14 Appendix - Findings with overinclusive quotes. A long version of qualitative findings with overinclusive list of supporting caregiver quotes.

The analytic themes and their subthemes (in bold) are supported with quotes. Summary supporting quotes (primary level data in the form of first-order constructs) are indented and italicised.

Theme 1. Cultural values and beliefs

The cultural context of caregiving was seen to be foundational for the caring experience with cultural beliefs, norms and socialization, religious beliefs and values (perceived by carers and their observed manifestations supported within one's culture) as motivating factors for caregivers to provide care, even in the changing cultural contexts (acculturation).

This analytic theme includes five main subthemes: cultural-specific norms of providing or seeking care; cultural socialisation (socialization/upbringing and expectations around care); spirituality and religion; acculturation; cultural aspects of illness perceptions.

1.1 Cultural-specific norms of providing care

This subtheme describes the implicit cultural value system embedded in the cultural context and culturally induced beliefs enshrined as norms that were seen to have directed the behaviour of caregivers.

A variety of culture-specific norms were found to govern more than one aspect of caregiving conduct (behaviour as the most obvious but also emotion and cognition). They were grounded in cultural values and social beliefs around informal care provision within their family and/or communities [1–24]. One of the most obvious norms was a Confucian-inspired notion of filial piety present in Asian cultural context (filial piety as a cultural norm) - regarded as the fundamental principle in Asian (e.g., Korean, Chinese, Thai, Taiwanese) social life, even enshrined as a norm in law in some cases (e.g., in The Korean Civil Act enacted in 1958). Filial piety was understood as a traditional and current practice through which older people are respected both within the family unit and in the wider society. Filial piety was also related to mutual exchanges and understandings shared between generations [2,4,5,8,10–12,17,19,21,25–31].

'In my view, this is a natural thing, taking care of my sick parents. For me, this is like eating and drinking, you should do so without asking, just like a father should bring up the offspring. I think it should be like this.' (Chinese CG) [12]

‘It is part of our tradition and culture for a wife to take care of her husband until he dies.’ (Chinese CG) [7]

Cross-cultural studies, such as Harris and Long (1999), gave insight into the significance of cultural norms. The aforementioned study comparing a sample of Japanese and American male carers demonstrated that amongst the Japanese carers, birth order and obligation to their parent (based upon the notion of filial piety) played a significant role in assuming the role and its continuation (eldest son and/or his wife; if the daughter-in-law is available). This was compared to limited evidence of cultural expectations of American sons that they become the caregivers, since it is most often regarded as a women's role. Cultural and social expectedness of assuming the role within the Japanese carers was informed by a ‘position to take care of the elderly (*mirutachiba*)’ [3]. ‘Mirutachiba’ implies that one’s position in the family (i.e., daughter or daughter-in-law) and/or the context within which the relationship between the caregiver and care recipient exists, determine who assumes the caregiver role. In other words these are cultural, patrilineal and primogeniture norms which are ingrained in carer socialisation - women know they may need to provide informal care if they marry the first son [3,4]. The caregiving duty was persistently recalled as taken for granted as part of traditional culture in the wider Asian context [9].

‘We [he and his siblings] hadn't talked about what to do before my mother was sick. I'm the oldest son, so everyone just assumes we [he and his wife] would take care of.’ (Japanese CG) [5]

‘It’s because I married the first son… I had the idea that one day I had to take care of his mother…’ (Japanese CG) [4]

‘As a son, taking care of my parents is my responsibility. Sometimes, my sisters come back home to care for my father, but they have already married out [of the family]. They are guests. It's not their responsibility.’ (Thai CG) [8]

In Thailand, the accounts provided demonstrated that daughters are expected to bring their husbands into their family system and continue to cultivate their parents' land, while sons move into the wife's family system. Therefore, there was an expectation that the youngest daughter would remain in the household (even after her marriage) and would provide care for her parents until they die [15].

‘No we haven't discussed it. I am the youngest daughter…’ (Thai CG) [15]

In a Nigerian context a norm of caregiving for a relative obliged individuals to provide care and inhibiting them from abandoning a care recipient no matter the nature of the illness [13].

In a study of Arab and Moslem caregivers in Israel another cultural norm was seen whereby responsibilities for care were divided among several people in the system, regardless of gender [6]. Similar to that seen in Japan, a study within a Turkish and Moroccan communities found that family care was primarily handled by the eldest daughter or the wife of the eldest son [24]. In a study of carers in a Surinamese Creole community, it was also mainly the eldest daughter who was expected to take care of her parents [24].

'Abandoning a blood relation is not done in our culture because blood relationship is very tight.' (Nigerian CG) [13]

'… if anything comes, if anything happens – how do I put it to you – I'm the eldest in my family; whether the rest do it or not, it doesn't matter to me, I will.' (Singaporean CG) [10]

The implicit value system embedded in the cultural context determined the experience of caregiving, where caregiving can be seen as natural, in many cases even essential and central to identity [1,5,7,11,12,16,20,21,24,25,27,32–35]. Cultural values comprised a distal factor in motivations to provide care that influenced various parts of caregiving experience, including motivations for providing care [6,10,11,15,16,20,24,25,27–29,31–39]. Cultural values instilled in participants constituted the basis for the sense of obligation to provide care and were shaped during specific socialisation [37] – this links to the *cultural socialisation* theme discussed below. The value system upheld the people's common concern for filial piety, commitment to the caregiving role, caregiving motivation and affirmed the validity of traditional cultural caregiving practices [11,39]. Moreover, a subtheme '*acculturation*' also showed that cultural values were still present and also shaped caregiving when facing a new cultural context, for example, when relocating to a new culture (e.g., Chinese immigrants living and providing care in the USA) or providing transnational caregiving (e.g., Chinese carers living in the USA but providing distant care to their recipients living in China) [16,28,31,33,40]. Cultural values refer to traditional value of filial piety (Hyo), filial respect and piety (*cóhiếu*), values present in philosophical and religious systems (e.g., Confucianism, Buddhist heritage, Christian model of family love and attachment) [2,4,5,8,10–12,15,17,19,21,25–31,41–43]. Other examples of cultural values which were identified include: the value of *marianismo* ('*self-sacrificing mother'*) constituting a basis for traditional gender role norms in the Mexican family based on the emulation of the Virgin Mary in the Catholic religion [34]; the cultural concept of yi (rightness and responsibility) in Confucianism [32]; Pakistani values of honouring the position of older adults in the family [36]; the concept of *'Kathany ukatawethi'* in the Thai culture which refers to the concept of repayment to parents by children, a value firmly ingrained in the Thai culture [15].

''I think the part of our Chinese culture, that one has to take care of and respect elderly people, is right. Conversely, I do not know how western countries justify this, explain this [not taking care].' [37]

‘It just comes naturally . . . It’s ingrained in our culture.’ [33]

‘But the Koreans who immigrated a long time ago still preserve the traditional Confucianism. […] the way of their eating, dressing, and housing seems to be very Americanized, but the way they think is not.’ [28]

‘It is the Islamic way of living. We look at other peoples’ situations. We are not focusing only on ourselves.’ [6]

1.2 Cultural socialisation (Socialisation/upbringing and expectations around care within one’s culture)

This subtheme more explicitly addresses the incorporation of cultural values promoting informal care provision within the family and fostering caregiving through exposure to the caregiving model(s) observed and expected in the family/society. This process of behavioural modelling was embedded in an individual upbringing [2–4,11,12,20–23,27,30,33,37,44–48]. This subtheme highlights personal socialization and the early creation of a sense of responsibility, a preparation for the role [23]. A sense of expectedness and preparedness for the caregiving role – based strongly on socialization as a distal determinant – played a significant role both in motivations to provide care and willingness to continue the expected role [3,11]. This was particularly evident and salient in the accounts of Asian caregivers but was also noticeable in European, American or Canadian carers’ accounts [3,11,20,27,34,47,49,50].

‘I always saw the way my grandmother took care of my uncles and my aunts. And the way my mom . . . my mom ended up . . . 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.’ [47] (Mexican culture)

‘I knew what we were brought up to do, what our obligations were, and that was taking care, cooking, cleaning, so it’s something that comes natural.’ [47] (Mexican culture)

‘I've always been involved in caring, that's how we were raised.’ [46] (Francophone Quebecois)

Incorporation of Asian (e.g., Korean, Chinese, Japanese) values within socialization supported and encouraged the development of filial responsibility from an early age. The concept of filial piety was conveyed to people through socialization, i.e. school education, family participatory teaching and informal demonstration, as well as various media of oral transmission (e.g., national media, portrayals in TV and radio) and rituals from and the public 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 with shared characteristics; the young are educated about it through exposure) [3,11,20,33]. Caregiving expectations were operationalised through the exposure to aforementioned experiences. Thus, for many, anticipating the caregiver role as a result of filial obligation was not striking (e.g., Japanese '*mirutachiba'*) – for example, for the Japanese women caregiver was an expected role, but for the American women it was not [3].

'I don't know whether it's the Japanese in us because we're just raised that way for some reason'. [22]

'It is my duty to take care of them. As Chinese, we received this kind of education.' [33]

'Most Chinese were brought up under the education that Hsiao [i.e. filial piety] is the most important virtue one should have.' [20]

'It's what we learned from outside, like school. It's also a personal feeling of myself towards my parents.' [20]

In broader terms the caregiving model (i.e. actual behaviour which may exemplify cultural norms and values) witnessed within one's family was seen to influence individual caregiving motivations [6,33,51]. Grandparents or parents (or other family members) act as a role model for subsequent generations by virtue of their looking after ill family members [12,33,51]. This perception was seen to be deeply rooted in culture and/or family model and values, thus the quotes often expressed the caregiving as arising 'naturally' without conscious thought [12]. Caregiving was fostered through exposure (i.e. role modelling) – it was a learned process from continued observation of close relatives' caregiving behaviours and skills, sometimes passed from female relative to female relative [47]. Role modelling by the caregiver's relatives influenced the caregiver's commitment to caregiving [33].

'Yes, naturally, naturally. Like you know, when we were young, we saw our parents taking care of their sick parents and it is just like a natural thing you just saw all the time.' [12]

'I saw my grandma and my mom doing this, and I thought it might happen to me. So it's just that way.' [33]

'My mother took care of my grandmother for several years when I was a teenager . . . this becomes part of you.' [6]

I've lived in the Philippines, and I've seen how people care for their parents and how important it is. I've sort of carried that and kept and treasured that.[33]

'[Those] smaller children who know how to cook do some of the cooking when the adults are away. When the older person and the [primary] person[s] providing the care lives in different homes, the [smaller] children carry the food from the caregiver's home to the older person's home.' [45]

Cultural norms governing the caregiving conduct of a society were seen to be so deeply internalised in socialisation that self-identification of being a carer was not described as unexpected [3].

'My mother also took care of her mother-in-law. I have seen all of them. So on the one hand, I know it is really hard, and . . . . Because I saw all of these, I thought it is atarimae no koto [a matter of course]'. (Japanese CG) [3]

'It's just—I think it's something we don't ever prepare for. It's something we get thrown into.' (American CG) [3]

The findings can also be referred to widely analysed dimensions of individualism-collectivism, especially in cross-cultural psychology [e.g., 54], where individualistic cultures are characterised by a focus on individual needs and relative detachment from relationships and community whereas collectivist cultures defined by the importance of relationships, roles and status within the social system. However strong cultural socialisation was seen to be an essential factor in motivations for caregiving, variation in individuals' model of upbringing could also act as influential. For example, whilst American and Swedish contexts typically offer individualistic cultures, for some study participants their own upbringing resembled more collectivist caregiving models and this helped shape the future caregiver commitment [53,54].

'It's been rough, but as for me taking care of her, it is the way I was brought up.' [54]

'Thus, it's one's personality and how one is brought up and how...' [53]

1.3 Spirituality and religion

This subtheme represents findings that various religious and spiritual beliefs were expressed as either the reason for initiating or maintaining the motivation for caregiving.

Many studies reported that religious beliefs and values, where present, constituted an essential motivating factor in informal caregiving [6,10,13,24,26,27,30,36,41–43,50,55–57], with various religious or spiritual teachings represented, predominantly Confucian, Buddhist or

Christian thoughts [4,8,11,15,19,24–28,36,40–42,46,56,58]. Apart from these widespread religious beliefs, other spiritual underpinnings were also revealed where caregiving was seen as: a Vietnamese way of appeasing the ancestors and gaining their blessings and approval [27], an African obligation towards ancestors to 'fulfil blood relations' through caring (a way of showing reverence to ancestors' spirits) [13], a Pakistani obligation to care related 'sa'adat' (a sign of good fortune) and 'sawab ka kaam' (virtuous deed) [36].

'I live according to my faith, faith in God. For instance, there are people who call it God, people who call it the Spirit, people who call it the Creator, people who call it Buddha. Well I believe very much in those things being able to give me more blessings. The second thing is - - for example, when you ask about experience to help your mother, you should remember the word "sacrifice." For example, today your friends invited you [the son] out but your mom needs you, so you sacrifice the fun to stay home to make your parents happy. That's sacrifice. Like us coming here in our old age. We don't quite fit in and feel very sad, giving ourselves to Jesus we must sacrifice for our children. Otherwise, sitting around and worrying would make us mad.' [27]

'It's my task as a daughter. I also have a chance to do good things and save my place in heaven doing this job.' [27]

'We take advantage to "clean ourselves up" now and we will have a place in heaven later.' [55]

'God sees, He sees and remembers. One day I will be rewarded.' [6]

'He is not only my father he is the Son of God . . . [and because of that] he should receive the best care I can possibly provide.' [6]

'For helping others I will get closer to God. God will bless me and my children will benefit from the good I do.' [56]

'What it means is that the individual has failed his/her ancestors and the person's ancestors can curse him/her because he/she has not represented them well.' [13]

'To care for our parents is a source of success in both the worlds—this one and the world here after.' [36]

‘As Muslims, we believe that the road to paradise - which is something I also want of course, as a believer – is under your mother’s feet.’ [24]

As seen in the aforementioned quotations, the power of and the belief in God’s will was a significant motivation to provide care and to continue providing it [33,51,56,58,59]. Mahilall (2006) referred to the belief in God as an intrinsic motivating factor.

‘I mean we are put on this earth for a purpose and I figure this is our purpose. God put us down here to take care of someone or to help someone.’ [59]

‘It is too much for me. But I am looking at this from God’s point of view. It is His purpose, and that is for my faith.’ [33]

‘My belief in God makes me do this work – I am God’s hands, His merciful servant.’ [56]

Apart from prevalently mentioned ‘God’s will’ as an explanation of caregiving commitment, another belief was also identified, that of karma. Caregiving seen through the lenses of karma reflected the following understanding: if you have to pay much to someone but you do not receive back equivalent rewards, the reason must be that you owed the person in their previous life. The only way to prevent a difficult future life or rebirth in lower realms (e.g., realm of ever hungry demons) is to repay the debts through caregiving [8,15,20,27,60].

‘I care a great deal for the elderly. I love and care for them a lot because I believe that there is karma in everything that we do. We have to think that later, when we are old, we will also reach that road too. So now, we love and help the elderly so that later on, God will also provide another person to help us in return.’ [27]

‘I don’t know in which previous lives I had owed all these debts, but I have to payback willingly anyway.’ [60]

‘I think I must have done something bad to her in my previous life. That's why I need to pay her in this life. This is what Buddhism said about Yeh- Jang (the past sin as a present obstacle). You just cannot run away from heavenly will. What people do, heaven is watching.’ [8]

Religious and spiritual values and beliefs were seen to have given rise to a sense of *religious duty* which – conversely to the factors presented only in relation to beliefs – acquired more behavioural attributes of a sociocultural construct considered as a form of extrinsic motivation to provide care [13,24,40,43,46,49,61,62]. This religious and moral compulsion to provide care for family is broadly defined within a specific religious context [49]; social responsibility/obligation attributed to common religious beliefs on caregiving in the society, for example gaining 'sevap' - good deeds in Islamic religion [62]. A different explanation may suggest that religious feelings are translated into moral values concerning caregiving duties perceived as morally expected and/or sanctioned by the supernatural force [46].

'I would have felt very un-Christian turning my back on my parents and I think my husband would have, too, just because that is the way we were brought up.' [43]

'I am a very short-tempered person but never talked to my father this way because there is a sense of 'Khuf e Khuda' (fear of God) that abstains me from doing so.' [36]

'Our traditional care system is embedded in the African traditional religion as practiced in our area in which it is an obligation to ones ancestors to take good care of sick family member/relation in the belief that the satisfied ancestors would favour their descendants who fulfilled their obligations to blood relations.' [13]

1.4 Acculturation

This subtheme refers to adjusting to a new culture while sustaining, seeking or finding linkages between previously acquired traditional cultural values and new cultural values shaping the way care is provided.

Such processes of adjustment were referred to in several studies [16,28,31,33,35,40,45,63] including many where Asian people had emigrated to North America [16,28,31,33,40]. Pre-existing cultural values may be challenged in a new cultural context, with evidence suggesting that whilst pre-existing values still remain an important source of motivation and willingness to provide care there is a noticeable shift from '*cultural certainties*' to '*important beliefs, norms and emotions*' as the '*certainties*' have been destabilized [63]. Accepting new cultural values did not necessarily mean discarding old cultural values and preserving old cultural values did not necessarily mean rejecting new cultural values [16,28,33,35] however the balancing of both created dilemmas and tensions in immigrant families. Whilst pre-existing values still motivated these individuals to provide care, an understanding of informal care provision in the new culture/country faced needed renegotiation and restructuring; for example, some carers found themselves able to transcend traditional, cultural values of filial piety by incorporating formal care services into their caregiving arrangements [16,31,40,45]. These coexisting cultural norms and values are evidenced in the contradictory accounts given by the carers, e.g., an influence of American liberal culture and Vietnamese culture [31].

'I don't want my children to take care of me. I want an independent life with dignity.' (Korean CG) [31]

'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. It's the same.' [35]

'I think it is inhumane not to take care of my old parents.' (Korean CG) [31]

'My children ... are likely to grow up with philosophy and attitudes that are different from what I know [about elder care], that is, children ... [taking] care ... of the financial and physical needs of their elderly parents.' [45]

'Ghanaian culture is changing,...by the time I become very old there may be nursing homes in Ghana so I wouldn't have to bother my children with [elder] caregiving.' [45]

A less frequent view referred to a perceived disconnect between western and traditional medicine, i.e. between available and preferred formal and informal care services. For example, the use of both conventional and traditional medicines by the Vietnamese is commonplace [35], yet, some carers indicated that linkages between these two health/healing systems are lacking, making it difficult to access the type of care that is congruent with caregiver and care recipient belief systems [13,35,45].

'It is our tradition to go for divination if a family member is sick especially if the sickness is a strange illness like HIV/AIDS.' [13]

'But my husband's brother said that now my mom-in-law must need to hear the doctors because the doctors give her medicine and something and he didn't want to make trouble with the doctor. He didn't want to take her to the Chinese person to do that [anymore.]' [35]

1.5 Cultural aspects of illness beliefs

This subtheme describes the impact of sociocultural illness representations on the caregiving experience in motivations for providing care, including a caregiver sense of expectancy and preparedness to care, stigmatisation of care recipient's illness or the lack of respect and understanding towards the care recipient demonstrated by society.

The cultural representations of certain health conditions, i.e. lay models of illness [64], were found to influence motivations and willingness to provide care, underlie the social embeddedness of caregiving, a sense of expectancy and preparedness for the role. Additionally, on a sociocultural level certain illness perceptions shared by the society were a source of stigmatisation which made caregiving a very difficult experience for some, and interfered with caregiver motivations and willingness to provide care. For example dementia was perceived as social stigma in China [65] or believed to be contagious in Pakistan [36]. Such beliefs resulted in familial and social isolation of some caregivers which negatively interfered with their motivations for caring, i.e. the perceptions led to stigmatisation (and fears of further stigmatisation) and lack of support which in turn was experienced by caregivers (these already engulfed in the role) as painful but at the same time motivating in providing care [6,19,66]. A study by Pang and Lee (2019) demonstrated a strong stigmatisation of dementia in Chinese culture - having a family member with dementia was perceived as a 'loss of face (mianzi)' (connected with feelings of shamefulness), especially when the family member had early onset dementia – it was believed then that the care recipients had done something bad in their past life. Caregivers felt the sole people feeling responsible for supporting their recipients. However, it needs to be acknowledged and subject to further investigation whether stigma and the expectation of stigma could prevent caregiving as data from people who relinquished caregiving was not obtained in this review.

'We [my husband and I] felt that we were being stigmatized by others [our friends and neighbours]. For example, one of our neighbours always asked him: 'Who is she[caregiver]?' My husband replied: 'She is my mom.' Then, he [the neighbour] laughed. I felt embarrassed. . .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.' [65]

'Sometimes my wife [the care-recipient] told me that she was useless and she wanted to die. I would encourage her and said: 'Why do you have such an idea? We should treasure every moment in life. Now, I treat you very well. I take care of you every day. You don't have to worry anything. Just live your life to the fullest.' [65]

Sociocultural perceptions of care recipient's illness were also manifested as the lack of respect towards the care recipient shown by some society members due to specific, negative social perceptions of illness, as seen above. The data demonstrates that these perceptions comprised a source of great concern, anger, agitation or sadness for the carers (as well as for care recipients). Therefore, we speculate this may have also influenced caregiver motivation to provide care, either positively where the perceptions promote understanding and eventual support or negatively, where the perceptions lead to stigmatisation and lack of support [6,19,66].

'It is so easy to lose respect for human beings who act a bit different and maybe are less bright that the rest of us. I have discovered how my mother's friends talk to her and I think it is so embarrassing and degrading.' [66] (Danish carer)

'People here think he is crazy. . . . This is why I do not let him out of the house. . . .So people will not be able to make fun of him, call him names . . . it is not good for the family to be known as having a mental illness among its members.' [6] (Arab Moslem carer)

'I do not know what is wrong with him. People say he is crazy. . . . He acts differently than he used to, but I do not think he is crazy. . . . He is not crazy. I think he is just old. There are days he is okay, but there are days he is not. . . . I am not sure.' [6]

Theme 2: Societal norms and perceived expectations

The impact of norms and perceived expectations on caregiving was seen at both a personal (individual) and a collective (public) level. This was evidenced in two broader groupings: (a) roles, norms and expectations specifying what is societally normative in terms of caregiving and (b) formal resources, services, policies (systems). This theme incorporates five descriptive subthemes, i.e. within (a): seeking social recognition and conforming to societal pressure; gender-specific roles; within (b): social policy intent and underpinning assumptions; perceived limitations to formal support provision and services; avoiding institutionalisation.

2.1 Seeking social recognition and conforming to societal pressure

This subtheme is further split into evidence that emerged around (i) seeking and receiving social recognition for displaying a socially normative caregiving behaviour, (ii) a concurrent expectation and desire to be seen as acting in a socially acceptable way by providing care.

There was a need for social recognition and praise in order to sustain and/or create a picture of being a 'good carer' with a desire to be seen as such in the society [20,45,56,65]. However, the exact characteristics pertaining to the picture of a 'good carer' did not emerge in the evidence (neither from first- nor second-order constructs). Appreciation shown towards caregivers by other members of society was shown to enhance willingness to provide/continue to provide care and acted as an additional motivating factor. This included sibling appreciation, appreciation shown by care recipients, and compliments from other community members[17,24,43,67].

'It was nice to know someone appreciated what you've done.' [43]

'All the neighbours here were watching. Everybody was saying, wow, what a good daughter he had…' [17]

‘When I hear him talking about me and about the care I’m giving, that is very fulfilling.’ [14]

‘I know that my work is of great value, that she would not be able to live at home if it wasn’t for me. And everyone says that, neighbours and others we know.’ [67]

‘Even my siblings appreciated what I have done to my wife.’ [65]

It appeared that caregiving was upheld due to the perceived public opinion towards caregiving responsibilities combined with a concurrent underlying societal expectation and desire to be seen as acting in a socially acceptable way. Pressure from others left little freedom of choice because deviation from societal expectations had anticipated negative consequences such as less respect and/or disrupted relationships both within the family or the broader community. [4,6–8,13,14,24,25,28,30,31,36,42,55,60,68,69]. This links with the previously described *cultural values* with distinctive examples including: a Korean way of thinking about caregiving in terms of being ‘self-conscious’ or ‘face-saving’ which could lead to family hiding a nursing home placement from others in their community because of the social norm of providing care predominantly within the family [28]; a study of Pakistani families where those who opted for institutionalization of their recipients were considered as unlucky, ill-fated and sinful [36]; in the context of Turkish, Moroccan and Surinamese Creole communities, carers needed to reckon with condemnation from their communities if a decision was made to institutionalize the care recipient [24]; and, in Ghana, ostracism (social sanctions) was reported as a punishment for caregivers who did not want to provide care [14]. Whilst noticeable in these collectivist cultures, a study conducted in Sweden [69] demonstrated that even in more individualistic cultures carers felt the expectations of friends, loved ones and professional healthcare staff to accept the caring responsibility even though they did not actually want to provide care.

‘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.’ [28]

‘If you don’t show respect, people will insult you. The sanction of disrespectful behaviour is ostracism, disrespect being paid back.’ [14]

‘My culture doesn’t accept changes. They expect you to do what is traditional. I can’t decide how I want to care for my mother because they consider it a bad choice. If I share the care for my mother with a professional, they’ll tell me I’m a bad daughter for not caring for my mother after all she has done for me’ [24]

‘We don’t want to be blamed for being bad children who don’t take care of their parent, particularly me, being a bad daughter-in-law.’ [31]

'If you take good care of your elderly parents and other family members, people in the community respect you. Especially, if you are able to build a good house for them you raise their status, which in turn earn you more respect.' [45]

2.2 Gender-specific roles:

The subtheme considers evidence of gendered social and cultural norms and expectations of informal care provision which was apparent in a vast number of caregiver accounts. In many countries caregiving has traditionally been considered women's responsibility, constituting a social norm [2,4,7,10,13,17,21,23,24,35,36,38,42,44,45,47,53,54,61,63,68,70–77]. Gendered social norms and expectations typically focused on women (as '*boys are unlikely to help'* [76], p. 302) with female-centred care networks [44] which, depending on the specific sociocultural context, included daughters, daughters-in-law and wives; sometimes ordered in a hierarchy of expected caregiving roles (e.g., spouses, daughters, daughters-in-law) [73]. One study demonstrated that gendered marital obligations were supported by current government policy (pertaining to social welfare and services for the elderly) towards elderly people in Hong Kong [7]. Caregiving was often an important part of a person's gender identity [38], with a basis in the socialisation process. Female gender determined a sense of duty and adherence to such prevailing cultural values and norms were thus part of the discourse around gendered care provision [73]. Muoghalu and Jegede (2010) found that females were more willing to care and to continue to care than males who were described more as contributing to the family through employment and financial contributions.

'When I was young, I was taught that taking care of the in-laws is a priority for a married woman.' [2]

[son-in-law] 'I stand back and let her do it. When she needs me, I'm there. When she wants me to do something, I'll do it, but I'm not going to get involved if I don't have to.' [23]

'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.' [44]

'I do it out of my own personal feeling of what is the right thing to do. I guess it's a moral thing because she's my husband's mother. If it were anybody else, it would be "absolutely not, no way.' [daughter-in-law] [23]

The belief that caregiving is 'women's work' implying they are more competent caregivers than men can be shared by both women and men [21,53,73]. This perception of women's 'natural' affinity for the role appeared ingrained within some cultural values.

'He's a man. He doesn't realise…' [76]

‘Well, I think they [women] have a little more feeling for it, I believe. Yes, I think so.’ [57]

‘Yes, but, yes, I think so, the fact that women are more soft and caring than men. I think. It is well rooted in a woman's nature. Childbirth and that, maternal instinct and stuff, huh. Empathy and stuff. I think that there is a little genetics also, so to speak.’ [57]

A less common view highlighted that the gender of the care provider bore less importance and that men felt more competent in particular areas of caregiving depending on the caregiving tasks, however, this conclusion derived exclusively from studies with only male carer samples [53,78]. In one study, a single male caregiving parent felt that his contribution to the care of his son went unacknowledged due to perceived social perceptions [78].

‘No, I don’t think so, I don’t think so. If I talk to my daughter, my wife, with others, in other words with women, about what they think, what they would do, I don’t think they would do any better than I have done. I don’t think that they would cope more easily.’ [53]

‘In these situations, when you need to carry someone, you have to be strong, and so on. That can be an advantage. Often guys are a little stronger. My sister would never have managed to lift our mother, even though she is not very big, so yeah, it's right heavy anyway to lift her. Other-wise, I do not know if it is, if it is an advantage to be the son. No, I do not think that it is. It is, well, just that, that one is a little stronger physically.’ [53]

‘The most difficult thing I think was initially getting other people to accept that I was the sole parent, when I went to his school, or when my son had to go to the hospital or taking him to the doctor appointment. I was not readily acknowledged as the parent. I was either an uncle or a brother; I was everything except for the father.’ [78]

2.3 Social policy intent and assumptions underpinning this

This subtheme relates to policy approaches (relating to caregivers, health and social care provision, supporting people with complex care needs and caregiver employment) and their intent and their underpinning sociocultural assumptions. Assumptions that carers will provide care out of love, leaving no place for those who may not want to care, may for example underpin social policy in the Australian context [79]. The visible rhetoric seen in the aforementioned study is that if most informal carers provide care out of love, by implication those who do not provide care must either not love their family member ‘as much as they should’. Furthermore, such rhetoric might suggest that love is the only or main motivation for care provision. Such assumptions were thought to have created an emotive moral discourse for carers, strengthening extrinsic motivation (imposed obligation, feelings of the lack of choice), while at the same time decreasing intrinsic motivations [79].

‘Most carers provide care out of love and believing they can provide a better quality of life for their family member or friend than anyone else. In many cases carers provide care because the demand for formal care services far exceeds supply and there is no alternative. (Commonwealth of Australia, 2011, p. 17)’ [79]

‘An increasing number of partners are living longer, which could increase the availability of informal carers. (Productivity Commission, 2011, p. 57)’ [79]

Informal caregivers were considered by the government as a valuable social and economic resource which should be preserved. The rhetoric expressed in one study [95] was that supporting carers (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 government. 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) [11], leaving no policy consideration of economic (least personal) ability of family to meet the costs of caregiving (and assess caregiver willingness to provide care).

‘Without support and assistance, carers can burn out which can then mean greater reliance on more formal forms of care’ [79]

In Korea, there is an implicit lawful obligation or encouragement for adult children to provide care for their parents: The Korean Civil Act (Civil Code, enacted on February 22, 1958) declares that children have the duty to support their parents who are not financially independent and moreover , the law encouraged the traditional heritage of filial piety and its application to informal caregiving as one means to resolve the challenges of the ageing society [11].

‘Persons eligible for assistance shall be those who have no person liable for supporting them, or if any, he/she is either unable to support or [is] incapable of supporting them . . . ‘ [11]

‘The state and local governments shall endeavor to ensure that senior citizens are respected at home and in society by encouraging filial piety and create a social environment necessary for building democratic and equitable family relations by activating exchanges between generations and promoting understanding between generations.’ [11]

‘Recently, we observe a phenomenon that adult children become reluctant to care for their indigent parents as society’s rapid change creates the shift from the traditional extended-family system to the “Westernized” nuclear-family pattern. […] Therefore, [there is a need] to

encourage and support the practice of filial piety in order to revive respect for parents or filial piety consciousness as a universal human value.' [11]

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 [8,12].

'Hiring an aide at home cost us a lot of money every month. Almost half of our salary was gone. Compared to hiring an aide, a nursing home is cheaper.' [8]

'And I worry about the cost [about a nursing home]. I have no money and I don't know if I can afford it. I have no choice (sobbing).' [12]

Only in one study [17] was monetary incentive (i.e. governmental payments/welfare benefits) considered when exploring motivations to provide care and in this American study it seemed that the benefits played a secondary role in motivation: most '*didn't do it for money*', for many it was helpful, and for others it was essential.

'I needed a compensation, that was the long and short of it. I couldn't really survive without it.' [17]

2.4 Perceived limitations to formal support provision and services

This subtheme describes perceptions of formal services as failing to meet the needs of carers thus placing demand on the carers themselves to address the recipients' needs. Perceiving barriers to accessing formal services or considering them as ineffective in addressing caregiver and care recipients' needs [32,86] constituted the basis for the perceived lack of alternative care. The perceived limitations to formal support provision and services left no choice and this perception is key in motivating carers to provide care [1,6,12,16,35,40,45,46,55,57,77,80,81].

Carers expressed dissatisfaction with existing formal services provision [1,80].

'Sara (informal carer): I did the grocery shopping
Interviewer: Did you choose to do it?
Sara: No, there were no other options. The home healthcare service won't do it, they don't want to do anything with money. So I had to help them with everything that involved money. You know, people can't take it anymore, they are exhausted. And the municipality takes advantage of it, because in the end people give up and stop nagging.' [80]

Language (cultural) barriers may were found to decrease a caregiver's access to and utilization of formal resources, increasing the burden on these caregivers which in turn motivated caregiving [16,35,40].

'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.' [1]

'Although I speak some English I don't know medical terms. When my mom needs to see a doctor we have to ask someone from our church to go with us. I have to make myself available according to their schedule.' [16]

'I speak little English. . . . I hate having to bother someone to get help.' [16]

'Because they know our language and they can understand me, so they are able to explain things better to me. They are able to understand me more. The specialist – they only prescribe the medication because I don't know the language as much, so they can't explain things to us.' [35]

Lack of knowledge of formal support [12,57,77] comprised another limitation (and at the same time a motivator) and, even when knowledge of care services existed (day care or residential), there was not always an available space for the care recipient [45,46].

There is no social support. I don't know, I don't know, I don't know whom I can ask for help, and I don't know who can give me help.' [57]

'Well, where else could she go? She can't be alone in an apartment, I can't send her to a private residence. [...] We thought she could be placed in a government facility, but there's no room.' [46]

'In Ghana, even if you have your money there is no nursing home to go to; the only [type of] care is family care.' [45]

Lack of respite care services was considered as undermining the caregiver sense of burden and therefore the quality of the informal care provision, i.e. some caregivers expressed the expectation that was there availability of respite care, it would aid caregivers to cope with their caring commitments by giving them time out to pursue other activities, refresh and remotivate [6,81]. This relates to the subtheme of the utilisation of respite care in *coping* (discussed elsewhere). 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.

'If there was a place that he could be for a few hours a day, I am sure that would have been much easier for me. It is very difficult to care for him and watch him for 24 hours a day.' [6]

2.5 Avoiding admission to a care home

This theme describes the comparative perceptions of institutional (residential or nursing) care and that provided by families.

Negative perceptions and images of a nursing care placement were frequently reported by caregivers. Placement was seen as inappropriate – either due to cultural and individual values, lack of trust/confidence in the quality of provision or because of the fear of condemnation from the community they live in if they relinquish caregiving responsibility (which links to the subtheme exploring caregiver cultural values). Care home placement had negative connotations for many – even considering this option hypothetically could lead to guilty feelings or sadness. Institutionalisation was sometimes associated with a lack of love towards the care recipient. Preventing institutionalisation (i.e. admission to a care home) was seen as factor motivating caregivers to provide care themselves [12,15,16,24,28,31,33,37,38,46,48,51,63,70,71,76,81–85].

‘Maybe you could send your parents to a nursing home, if you have to. But I would never send my parents there; it’s inhumane.’ [31]

‘We are unfilial. We already are bad children if we send our parent(s) to a nursing home.’ [28]

‘So when her leaving was decided, my family wasn’t happy about it because they felt like they were sending her away like Goryeojang [the term refers to an ancient practice in Korea whereby an old frail parent was abandoned in the mountains to die]. *’* [28]

‘He’s my daddy and keeping him from a nursing home, I’d do anything.’ [81]

‘I just can’t see a person like her in a nursing home, or someplace where she’d be took care of.’ [84]

‘I was very sorry that I had to take her there. It was devastating. She cried and my family and I cried. . . . Our family was sad. If you think about it in a Korean way, we were very sorry. . . ‘ [28]

‘She was on her own a lot and I didn't want my mother in a home or a nursing home because I thought she would just go downhill fast. I just did it and that was that ... I don't think of it as a sacrifice' [85]

Anti-institutional feelings may be underpinned by the commonly reported social norm of family care, with assumptions that this is a ‘better’ option, for example perceptions that family care is more loving and offers more security and recognition for the care recipient, i.e. is more individualised and person-centred [1,6,16,21,24,31,48,79,86].

'Care is not . . . to be bought, not a service to be bought. It's a service we have to provide out of our mouth, and affection for the other human being.' [21]

'We have to take care of our own. No one's going to take care of my sister like I am.' [48]

'We will have to do it. We won't hand our family over to anyone else, it's our blood. We'll do it ourselves. We will try as long as we are here. We don't want anybody else to look after our family.' [1]

'I think it's very important, particularly in the case of my mother, who has dementia, that she should be cared for by family, by people she already knows. Above all, she needs recognised family members around her, somebody who makes her feel calm, somebody trusted, so I do think that's important.' [24]

Maintaining a familiar environment, needing to maintain the care recipient's dignity and privacy as well as fears of an outsider not providing the same quality level of care were also distinguishable reasons to avoid institutionalisation. [1,12,17,35,46,70].

'I don't want to send him to the nursing home. I don't trust anyone except me.' [12]

'For example, we are shy about [when] someone showers us ... as Vietnamese we're shy letting people shower us.' [35]

'If she was not in her own environment she would not be so well.' [70]

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B1 Appendix - The search strategy - search strategy commands applied within scientific databases

	Search Terms
1	(MM "Motivation")
2	motiv*
3	"motivation to care"
4	"motivations to care"
5	"motivation to provide care"
6	"motivations to provide care"
7	drive
8	oblig*
9	duty
10	filial
11	willing*
12	"willingness to care"
13	"willingness to provide care"
14	OR / 1-13
15	value*
16	"familism"
17	social
18	personal
19	ethnic*
20	cultur*
21	demographic*
22	diagnosis
23	illness
24	characteristic*
25	determinant*
26	OR / 15-25
27	(MM "Caregivers")
28	caregiver*
29	caregiving
30	family
31	relative*
32	spouse
33	partner
34	carer*
35	OR / 27-34
36	14 AND 26 AND 35
37	AB(14 AND 26) AND TI(35)

B2 Appendix - Additional literature searches

Type of source	**Data sources**
Unpublished and Grey literature	The Metaregister; www.opengrey.eu; www.base-search.net; Global Health (Ovid); Social Care Online
Contacting experts	Eurocarers – European Association Working for Carers; Carers Trust (UK); key authors (Val Morrison, Rachel Dekel, Diane Seddon, Giovanni Lamura)
Hand Search	Conference proceedings: - British Society of Gerontology Annual Conference, - Alzheimer's Association International Conference; Web of Science: - Conference Proceedings Citation Index- Science (CPCI-S), - Conference Proceedings Citation Index- Social Science & Humanities (CPCI-SSH); Reference list checking of studies that met the eligibility criteria; relevant systematic reviews retrieved by the search (retrospective reference list checking).
General searches	'Google scholar'
PhD Theses and Dissertations	EThOS; Open Access Theses and Dissertations

B3 Appendix - PRISMA (2020) Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
TITLE			
Title	1	Identify the report as a systematic review.	1
ABSTRACT			
Abstract	2	See the PRISMA 2020 for Abstracts checklist.	1-2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of existing knowledge.	3-5
Objectives	4	Provide an explicit statement of the objective(s) or question(s) the review addresses.	5-6
METHODS			
Eligibility criteria	5	Specify the inclusion and exclusion criteria for the review and how studies were grouped for the syntheses.	6-7
Information sources	6	Specify all databases, registers, websites, organisations, reference lists and other sources searched or consulted to identify studies. Specify the date when each source was last searched or consulted.	7
Search strategy	7	Present the full search strategies for all databases, registers and websites, including any filters and limits used.	7
Selection process	8	Specify the methods used to decide whether a study met the inclusion criteria of the review, including how many reviewers screened each record and each report retrieved, whether they worked independently, and if applicable, details of automation tools used in the process.	7-8
Data collection process	9	Specify the methods used to collect data from reports, including how many reviewers collected data from each report, whether they worked independently, any processes for obtaining or confirming data from study investigators, and if applicable, details of automation tools used in the process.	8
Data items	10a	List and define all outcomes for which data were sought. Specify whether all results that were compatible with each outcome domain in each study were sought (e.g. for all measures, time points, analyses), and if not, the methods used to decide which results to collect.	6
	10b	List and define all other variables for which data were sought (e.g. participant and intervention characteristics, funding sources). Describe any assumptions made about any missing or unclear information.	6, 7-8
Study risk of bias assessment	11	Specify the methods used to assess risk of bias in the included studies, including details of the tool(s) used, how many reviewers assessed each study and whether they worked independently, and if applicable, details of automation tools used in the process.	7, 9-10
Effect measures	12	Specify for each outcome the effect measure(s) (e.g. risk ratio, mean difference) used in the synthesis or presentation of results.	6
Synthesis methods	13a	Describe the processes used to decide which studies were eligible for each synthesis (e.g. tabulating the study intervention characteristics and comparing against the planned groups for each synthesis (item #5)).	6-7
	13b	Describe any methods required to prepare the data for presentation or synthesis, such as handling of missing summary statistics, or data conversions.	8-9
	13c	Describe any methods used to tabulate or visually display results of individual studies and syntheses.	8-9
	13d	Describe any methods used to synthesize results and provide a rationale for the choice(s). If meta-analysis was performed, describe the model(s), method(s) to identify the presence and extent of statistical heterogeneity, and software package(s) used.	8-9
	13e	Describe any methods used to explore possible causes of heterogeneity among study results (e.g. subgroup analysis, meta-regression).	10-11, 26
	13f	Describe any sensitivity analyses conducted to assess robustness of the synthesized results.	8-9, 11

B3 Appendix - PRISMA (2020) Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
Reporting bias assessment	14	Describe any methods used to assess risk of bias due to missing results in a synthesis (arising from reporting biases).	7, 9-10
Certainty assessment	15	Describe any methods used to assess certainty (or confidence) in the body of evidence for an outcome.	10
RESULTS			
Study selection	16a	Describe the results of the search and selection process, from the number of records identified in the search to the number of studies included in the review, ideally using a flow diagram.	10
	16b	Cite studies that might appear to meet the inclusion criteria, but which were excluded, and explain why they were excluded.	10
Study characteristics	17	Cite each included study and present its characteristics.	10-12
Risk of bias in studies	18	Present assessments of risk of bias for each included study.	9-10
Results of individual studies	19	For all outcomes, present, for each study: (a) summary statistics for each group (where appropriate) and (b) an effect estimate and its precision (e.g. confidence/credible interval), ideally using structured tables or plots.	N/A
Results of syntheses	20a	For each synthesis, briefly summarise the characteristics and risk of bias among contributing studies.	9-11
	20b	Present results of all statistical syntheses conducted. If meta-analysis was done, present for each the summary estimate and its precision (e.g. confidence/credible interval) and measures of statistical heterogeneity. If comparing groups, describe the direction of the effect.	12-19
	20c	Present results of all investigations of possible causes of heterogeneity among study results.	9-11, 26
	20d	Present results of all sensitivity analyses conducted to assess the robustness of the synthesized results.	9-11, 26
Reporting biases	21	Present assessments of risk of bias due to missing results (arising from reporting biases) for each synthesis assessed.	9-11
Certainty of evidence	22	Present assessments of certainty (or confidence) in the body of evidence for each outcome assessed.	9-11
DISCUSSION			
Discussion	23a	Provide a general interpretation of the results in the context of other evidence.	19-22
	23b	Discuss any limitations of the evidence included in the review.	24-26
	23c	Discuss any limitations of the review processes used.	24-26
	23d	Discuss implications of the results for practice, policy, and future research.	22-23
OTHER INFORMATION			
Registration and protocol	24a	Provide registration information for the review, including register name and registration number, or state that the review was not registered.	Provided in a supplementary file
	24b	Indicate where the review protocol can be accessed, or state that a protocol was not prepared.	As above

B3 Appendix - PRISMA (2020) Checklist

Section and Topic	Item #	Checklist item	Location where item is reported
	24c	Describe and explain any amendments to information provided at registration or in the protocol.	As above
Support	25	Describe sources of financial or non-financial support for the review, and the role of the funders or sponsors in the review.	2
Competing interests	26	Declare any competing interests of review authors.	2
Availability of data, code and other materials	27	Report which of the following are publicly available and where they can be found: template data collection forms; data extracted from included studies; data used for all analyses; analytic code; any other materials used in the review.	7-8, 9-11

From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. BMJ 2021;372:n71. doi: 10.1136/bmj.n71

For more information, visit: http://www.prisma-statement.org/

B4 Appendix - The eMERGe meta-ethnography reporting guidance

No.	Noblit and Hare's 7 phases	Criteria Headings	Reporting Criteria (what each step entailed in the meta-ethnography)
1	Phase 1 - Selecting meta-ethnography and getting started	Rationale and context for the meta-ethnography	As caregiving motivations are likely to be culturally-bound, it is important to enhance our understanding of cultural factors underlying the motives for providing care (or not providing it) and potential willingness (or lack thereof). However, no review has addressed this issue in a meta-ethnographic synthesis, which can provide more insight (explanations) about the way in which culture underpins caregiver motivations and willingness to provide informal care, i.e., the question of *how* culture shapes motivations, not only *if* it does, needs addressed. A review was registered as part of the wider systematic review at the Centre for Reviews and Dissemination – National Institute for Health Research at the University of York (PROSPERO): 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 qualitative 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, however, in line with the strategy for data synthesis described in the PROSPERO protocol (i.e., anticipation of different methods of synthesis). The meta-ethnography was applied to synthesise only studies focused on motivations and/or willingness to provide care that pertained to culture-specific norms of informal care provision.
2		Aim(s) of the meta-ethnography	(1) identify potential explanations for how culture underlies motivations and willingness to provide care, (2) explicate the possible interactions between ethnocultural factors, (3) develop a model that explains cultural determinants of motivations and willingness to provide care.
3		Focus of the meta-ethnography	This review sets out specifically to gain understanding of how culture underpins and shapes motivations and willingness to provide informal care. Two review questions are: What are the potential cultural determinants of motivations and willingness to provide informal care? How do these cultural factors shape motivations and willingness for providing informal care?
4		Rationale for using meta-ethnography	As cultural values and beliefs have been shown to influence the caregiving experience, the authors decided to deepen the understanding of how these cultural factors (specifically in terms of cultural-specific norms of informal care provision) influence motivations and willingness for providing informal care. As the main review question was concerned more with understanding of the mechanism ('how') and as the focus was placed on ethnocultural determinants, a more interpretive synthesis was required in order to understand how these factors shape the caregiver experience in motivations and willingness for caring. Meta-ethnography, thanks to its processes of translating studies into one another and synthesising translations, offers an in-depth and interpretative exploration of how potential cultural factors influence motivations and willingness to provide care through the

			construction of the theoretical model on the subject. The goal of meta-ethnography is to systematically synthesise a body of qualitative research to create a ‘whole’ greater than the sum of its parts, offering new conceptual insights while preserving the ideas from the original studies.
5	Phase 2 - Deciding what is relevant	Search strategy	The approach to searches combined both comprehensive and purposive sampling methods, i.e., studies pertaining to cultural-specific underpinnings of motivations and willingness for caring were selected purposefully for the meta-ethnography synthesis from the pool of 105 qualitative studies (sampled comprehensively) which reported on various determinants of caregiver motives and willingness to provide care in a different review (reported elsewhere and conducted by the authors). This is justified by the fully interpretative focus placed on specific studies that contributed added value over and above the general meta-synthesis of all studies, with a specific aim to provide explanation on how culture shape caregiving motivations and willingness to provide care, not only *if* it does.
6		Search processes	Search processes are reported altogether with the PRISMA statement. The selection of the studies for the meta-ethnography synthesis was purposeful – studies which related to cultural-specific underpinnings of motivations and willingness for caring were synthesised.
7		Selecting primary studies	Two reviewers (MZ, EB) selected 37 studies that reported cultural-specific underpinnings of motivations and willingness to provide care.
8		Outcome of study selection	Electronic searches identified a total of 9793 papers. After duplicate removal (N=4141) the remaining 5652 articles were screened by title and abstract. Following exclusions (N=5462), 190 full-text records were assessed for eligibility. Final exclusions (N=85) resulted in 105 eligible studies reporting on diverse determinants of motivations and willingness to provide care. Out of these, 37 studies pertaining to cultural-specific motivations for providing informal care were purposively selected for the meta-ethnography synthesis based on the review questions.
9	Phase 3 - Reading included studies	Reading and data extraction approach	Two reviewers (MZ & EB) applied Schutz’s conceptualisation of second- and third-order constructs whilst extracting the data. This first phase of meta-ethnographic synthesis (identification) was similar in position to the first phases of thematic analysis (although meta-ethnography approach does not require such formal methods for theme/concept extraction from the included studies but at the same time it does not exclude them). Primary study authors’ conceptual data (second-order constructs) was thematically grouped as to determine the concepts with similar meanings thorough open and selective coding, ensuring the context of the data (first- and second order constructs) was preserved in the wider review team (MZ, EB, VM, DS & RD). The key concepts and sub-concepts were compared within and across studies.
10		Presenting characteristics of included studies	Detail characteristics of the included studies are presented in meta-ethnography grids (in which also the content of second-order constructs of each concept is presented for each of the studies).
11	Phase 4 - Determining	Process for determining how studies are related	The translation synthesis process compared concepts individually, account by account (i.e., each account pertaining to each concept identified) in chronological order (i.e., study by study) as proposed by Campbell et al. (2003).

12	how studies are related	Outcome of relating studies	The concepts and sub-concepts were re-configured based on reciprocal translations. They were related to each other reciprocally.
13	Phase 5 - Translating studies into one another	Process of translating studies	When key concepts have been developed, with the identified concepts applied to the first study, the next study was synthesised based on the processes of two types of *translation* – reciprocal and refutational. Reciprocal translation refers to concepts across the studies which agree with each other and can be aggregated, whilst refutational translation pertains to concepts across the studies which conflict with one another. Having identified concepts from each study, search for the presence or absence of these concepts in all studies was conducted and presented in a table of the contribution of the concepts to each of the studies included in the review as well as meta-ethnography grids (in which the content of second-order constructs of each concept is presented for each of the studies). Then the translation synthesis process followed the approach to translation introduced by Campbell et al. (2003), as described above. This translation process was conducted by two reviewers and involved analysing the relevant emergent concepts (concepts and sub-concepts) pertaining to the cultural-specific motivations for providing informal care in terms of whether they agree with one another or not. After short descriptions of the key concepts had been developed, these were compared to identify any contradictions (refutational translation).
14		Outcome of translation	The concepts seemed congruent with one another, i.e. same as in a review by Britten et al. [45], it was clear that the concepts were not refutations of one another even if a particular concept was not identified in a particular paper or the terminology was not identical but the meaning of the categories remained the same. Therefore, the studies were related to each other reciprocally. The only exception identified related to the comparison between the concepts of 'Love and emotional attachment' compared with the concept of 'Cultural duty and beliefs of obligation'. Specifically, based on the distinction between the expression of love and the feelings of love, it was explored to what extent the feelings of love may stand in contradiction to the sense of obligation. Firstly, it was demonstrated that showing love and affection was informed by sociocultural norms and expectations (i.e., love may be an expression of the common cultural values and obligations) as well as it may play no part (e.g., caregiving daughters-in-law), as this may be influenced by different factors such as for example the caring relationship type (the concept was absent in 57% of the included papers). Secondly, when contrasting the reported feelings of love with the cultural obligation, the last appeared to be treated as a natural part of caregiver's life and mostly without negative connotations [6,18,21,28], suggesting that affects of love and emotional attachments to the care recipient may go in pair with a culturally-shaped duty to provide care, suggesting that caregiving obligations may constitute an inherent part of caregiving loving relationships [19,25,38].
15	Phase 6 - Synthesizing translations	Synthesis process	This final phase of the meat-ethnography synthesis process (development of the line of argument and the model) was conducted by the main reviewer (MZ) and was summarised in a form of a table containing the previously described concepts with a developed line of argument. The first reviewer (MZ) arranged (configured) concepts, second- and third-order constructs to build up a line of argument, i.e., a 'storyline' or 'narration' which provides an 'explanation' or 'theory' to the findings. In this process the most compelling explanation formulated by the first reviewer was introduced to the review team (VM, DS, EB, RD) who confirmed the preservation of the

			meaning between the first-, second-order constructs and the first reviewer's third-order interpretations. No alternative explanation was put forward by the other reviewers. A table was generated relating to the line of argument shows the reviewers' interpretations (third-order constructs) and second-order interpretations across all studies. A model, which encompassed these findings across all the papers, was developed and presented as a pyramid chart and described in the paper.
16		Outcome of synthesis process	The meta-ethnography synthesis enabled a development of the model of cultural motivations for providing informal care. Its significance is described in the Findings and Discussion sections in the main text. The context to which the new model can apply should be strongly informed by the basic study characteristic presented in meta-ethnography grids.
17	Phase 7 - Expressing the synthesis	Summary of findings	The main interpretive findings of the synthesis were contrasted with the review questions. The developed model which posits caregiver cultural self-identity in the centre of the theoretical framework was compared with the scarce existing research literature. The implications for research, practice and policy were suggested - this information is compiled in the Discussion section.
18		Strengths, limitations, and reflexivity	These are reported in the Discussion section.
19		Recommendations and conclusions	The findings of the meta-ethnography review bear implications for the theory development, research, practice and policy. There were presented in the Discussion section.

B5 Appendix - Data synthesis - detailed description of the meta-ethnography synthesis

Meta-ethnography was applied to synthesise qualitative studies focusing on the cultural aspects of caregiver motivations and willingness for caring, especially in terms of the cultural-specific norms of informal care provision. The synthesis followed Noblit and Hare's seven-step process of: getting started; deciding what is relevant to the research questions; reading the studies; determining how studies are related; translating studies into one another; synthesising translations; and expressing the synthesis (France, Uny, et al., 2019; Noblit and Hare, 1988).

Meta-ethnography synthesis consisted of three distinct phases and applied Schutz's conceptualisation of second- and third-order constructs. The phases were as follow:

- identification of relevant concepts in the primary studies (determinants of motivations and willingness to provide care) – congruent with the first steps of thematic synthesis;
- the description of second-order constructs;
- the description of third-order constructs;
- the previous two descriptions of concepts were used to build a line of argument.

The first phase of meta-ethnographic synthesis (identification) is similar in position to the first phases of thematic analysis. Primary study authors' conceptual data (second-order constructs) was thematically grouped (Britten et al., 2002; Britten and Pope, 2012; France, Cunningham, et al., 2019; Toye et al., 2014) as to determine the concepts with similar meanings through open and selective coding, ensuring the context of the data (first- and second order constructs) was preserved. When key concepts have been determined, with the identified concepts applied to the first study, the next study was synthesised using processes of two types of *translation* (Britten et al., 2002; France, Cunningham, et al., 2019; Gough et al., 2017) – reciprocal and refutational. *Reciprocal translation* refers to concepts across the studies which agree with each other and can be aggregated, whilst *refutational translation* pertains to concepts across the studies which conflict with one another. Having identified concepts from each study, a search for the presence or absence of these concepts in all studies was conducted. Table 2a & 2b present the contribution of the concepts to each of the studies included in this review. Meta-ethnography grids demonstrate the content of second-order constructs of each concept for each of the studies (see online S1 Supplementary File, below). The translation synthesis process followed the approach introduced by Campbell (Atkins et al., 2008; Campbell et al., 2003) in which concepts are individually compared account by account (i.e. each account pertaining to each concept identified) in chronological order (i.e., study by study). This translation process was conducted by two reviewers and involved analysing the relevant emergent concepts (and sub-concepts) pertaining to cultural-specific motivations for providing informal care in terms of whether they agree with one another or not. After developing short descriptions of the key concepts, these were compared to identify any contradictions (refutational translation).

The concepts seemed congruent with one another, i.e., the concepts were not refutations of one another and even if a particular concept was not identified in any particular paper or the terminology was not identical, the meaning of the categories remained the same. Based on this congruence, a line of argument was generated to provide further analysis and interpretation, integrating similarities and differences across studies to form a novel conceptual framework. This final phase of the meta-ethnography synthesis process was conducted by the main reviewer (MZ). During this the first reviewer (MZ) arranged (configured) concepts, second- and third-order constructs to build up a line of argument, i.e., a 'storyline' or 'narration' which provides an 'explanation' or 'theory' to the findings. In this process the most compelling explanation formulated was next introduced to the review team (VM, DS, EB, RD) who confirmed the preservation of the meaning between the first-, second-order constructs and the first reviewer's third-order interpretations. No alternative explanation was put forward by the other reviewers. A table relating to the line of argument shows the reviewers' interpretations (third-order constructs) and second-order interpretations across all studies (see Table in online S2 Supplementary File). A model, which encompassed these findings across all the papers, was developed and presented as a pyramid chart (Figure 2 in the Discussion section).

B6 Appendix - Meta-ethnography grids in which the content of second-order constructs of each concept is presented for each of the studies (Tables 1a-d)

Table 1a Meta-ethnography grid 1

Study ID / **Characteristics**	**Chao & Roth, 2000**	**Spitzer et al., 2003**	**Van Sjaak Geest, 2002**	**van Wezel et al., 2016**	**Globerman, 1996**	**Wallhagen & Yamamoto-Mitani, 2006**	**Parveen et al., 2011**	**Yamamoto & Wallhagen, 1997**	**Kim & Theis, 2000**
Sample	31 Taiwanese caregivers; all daughters-in-law	29 South-Asian and Chinese caregivers; women; different relationship types	35 African caregivers	69 carers of Turkish, Moroccan and Surinamese origin; different relationship types	16 Canadian caregivers, daughters- and sons-in-law	16 (9 American and 7 Japanese); daughters or daughters-in-law	30 carers of Bangladeshi, Indian, Pakistani or White-British origin; different relationship types	26 Japanese caregivers; daughters or daughters-in-law	30 Korean American caregivers; mainly spouses
Data collection	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face semi-structured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews plus focus groups	Cross-sectional, face-to-face and one-to-one semi-structured interviews plus focus groups	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Longitudinal, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face and semi-structured focus groups	Cross-sectional, face-to-face and one-to-one unstructured and semi-structured interviews	Cross-sectional, face-to-face, semi-structured interviews
Setting	Participants' homes or rehabilitation wards	NR	Various settings	NR	Mainly participants' homes	Caregiver's home or the research office of one of the authors	Support group centres	NR	Homes of the caregivers

Methodology and method of analysis	Grounded theory; Constant comparative method	Ethnographic approach; Content analysis	Interpretative ethnographic approach; Ethnographic descriptive analysis	Generic approach; NR	Qualitative interpretive approach; McCracken's long interview method (1988)	Grounded theory; Constant comparative method	NR; Thematic content analysis	Grounded theory; Constant comparative method	Descriptive qualitative; NC (Thematic/content analysis)
Study design	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Longitudinal	Cross-sectional	Cross-sectional	Cross-sectional
Country	Taiwan	Canada	Ghana (Kwahu)	Netherlands	Canada	Japan and the USA	The UK	Japan	The USA
Key concepts									
Cultural duty and beliefs of obligation	‘A married woman belongs to her husband's family and she should be obedient to him and devoted to the family.’	Close relatives feel obliged to provide care.	The social hierarchy of caregiving responsibilities being a basis for the feelings of duty. First – for children; second – a married person (adult child) lives in their own family house (*abusua fie*) – the care goes then to spouse (if the person is separated, then other relatives).	‘In both the Turkish and Moroccan communities, family care is primarily handled by the eldest daughter or the wife of the eldest son. In the Surinamese Creole community, it is also often a daughter who is involved in the care of a parent with dementia, but it does not necessarily have to be the eldest daughter; When Moroccan or Turkish immigrant men do provide	Engendered sense of responsibility.	Position to take care of the elderly (*miru tachiba*). ‘Miru tachiba implies that one’s position in the family (i.e., daughter or daughter-in-law) and/or the context within which the relationship between the care recipient and caregiver had evolved over time requires one to take on the caregiver role.’	Duty or obligation or responsibility to provide care; fulfilling cultural duties; no choice but to adopt the role of the caregiver as there had been no one else to carry out the care role.	A sense of responsibility.	Korean traditional social code – obligation versus attachment: ‘They viewed their caregiving role as natural and ordinary under the traditional Korean cultural norm, filial obligation for their care recipients with a sense of continuity with the past.’

				physical care, it is generally for male family members of their own ‘family line’ (their own father or uncle).’					
Repayment motive	A desire to repay by fulfilling the duty.	N/A	Care recipient’s previous conduct when upbringing their own child – ‘if the person is considered *akwakora bofo* (bad, old man), then he may not receive any care (divorce may be treated as misbehaviour).’	‘When caring for parents or parents-in-law, there is also a kind of reciprocity.’	N/A	Reciprocity as a factor.	N/A	Concept of a sense of reciprocity (individually).	‘The majority of caregivers denied considering their quantity and quality of caregiving responsibilities as repayment for what the care recipients did for them.’
Gendered cultural expectations	‘Women should be praised for displaying filial piety and taking care of her parents-in-law.’	‘Respondents felt that women were the most appropriate caregivers for elders as well as for children.’	‘Most of the practical activities performed for elderly people are, in fact, female tasks.’	‘Primarily a task for women.’ ‘To be seen as a good daughter or daughter-in-law.’	Sons-in-law’s motivation is reactive (they care when they’re delegated to do that), they care to maintain their marital relationships; daughters-in-law’s motivation is based upon female socialization upon which the	Dependent on the circumstances – care can be provided by both men or women, although in most cases (when there is an available daughter-in-law) these are women; in the USA men are less expected to provide care than women.	N/A	Caregiving as domain of (particularly) daughters-in-law.	N/A

					sense of responsibility is created; to protect the husband from suffering or to manage his suffering by caring for his parents.				
Religious and philosophical ideas	Religious beliefs were the reasons behind the provision of informal care.	N/A	Religious beliefs upholding caregiving duties.	Providing care as a religious (Islam for the Turkish and Moroccan participants, Christianity for the Surinamese) and cultural expectation.	N/A	N/A	Cultural and religious obligation.	N/A	N/A
Filial piety	Traditional cultural norm and personal expectation. No matter how hard caregiving is, filial piety has to be maintained (‘inevitable responsibility’).	N/A	N/A	N/A	N/A	Filial piety as cultural value ingrained in Japanese culture; no such counterpart in American culture.	N/A	Concept of a social debt in Confucianism (supraindividaully).	Traditional cultural norm of filial piety.
Shaping cultural identity	Women are expected to express filial behaviours with the desire to fulfil filial piety.	‘As mothers of the nation and reproducers of society, [women are] entrusted with the task of	N/A	Caregiving is principally a task for women; being a woman designates a person as a potential carer.	Female socialization preparing women for assuming caregiving	Caregiving as an expected career for Japanese carers, its social embeddedness and taken-for-grantedness (‘Those who	Culture invoked as an important factor when thinking about oneself as a carer.	Expectancy of assuming the role – due to patrilineal and primogeniture norms (women knew they may need to care if they marry the first son);	N/A

		maintaining cultural identity through educating the young and modeling their own [caregiving] behavior.’			roles in the future.	anticipate an eventual caregiver role can design their lives in such a way that it is relatively easy to accommodate’); caregiving unexpected career for American carers.		Maintainers of the cultural values: self-identity; moral obligation; coherence – based on the decision (e.g., when marrying the first son); internalized norms maintained by the society; feelings of empathy or pity.	
Rising demands of the contemporary world	N/A	Employment did not offer supplemental health insurance, family benefits, or flexible hours, it was difficult for caregivers to combine the role with the demands of a professional work.	N/A	N/A	N/A	N/A	N/A	Norms varying to some extent depending on the area of Japan and whether it’s more rural or urban area.	‘When their care recipients became ill, these caregivers had to provide patient care in addition to household chores’ (life in a different society and new area).
Familism and family- and community-based care	N/A	‘Belief that care is best carried out in the home by providers linked by sentiment and limited traditions of	‘Several people are usually involved in providing care.’	Family care as being more loving and as offering more security and recognition for the care recipient; institutionalising a relative may be	N/A	N/A	Fulfilling familial duties as well as fear of an outsider not providing the same quality level of care.	N/A	N/A

		accessing services.’		condemned by the community.						
Love and emotional attachments	N/A	N/A	Love, dedication, and affection towards a care recipient.	N/A	Affection in these types of relationships was not apparent.	N/A	Emotional attachments with the care recipient.	Attachment – emotional bond; ‘amaeru’ (indulgent love) changes into ‘amayakasu’ (offering indulgent love).	Insignificant role of the emotional attachment.
Explanation (second-order interpretation)	Motivations and willingness to care, based on the feelings of duty, are shaped by cultural norms (religion, filial piety) and socialisation in Taiwan.	Caregiving central to women and members of their ethnocultural community. Cultural values uphold filial obligations which constitute a powerful social imperative to provide informal care.	Motivations depend to a large extent on whether the CR provided to their own children before (a matter of reciprocity) and social norms governing the caregiving.	Caring motives are related to cultural and religious backgrounds and norms -caregiving for female carers is an expected task that they should carry out with respect and love; it is superior to professional care.	Motivation to care in a specific kin relationship – between children-in-law and their parents-in-law – derives from the engendered sense of responsibility, which is based on cultural expectations and socialisation.	Motivations for care based on cultural expectations shaping the sense of preparedness (or its lack) and felling of duty to assume the role. The differences in the ethnocultural content are seen between American and Japanese cultures.	British South-Asian caregivers’ willingness to provide care was related to fulfilling their cultural and religious duty whereas White-British caregiver’s willingness to provide care was due to emotional attachments to the care receiver and a fear of institutionalisation	Expectancy of assuming the caregiving role by daughters-in-law due to sociocultural expectations. Cultural values, self-identity, internalised norms and emotional attachment are crucial for the continuation of the role.	The Korean traditional cultural norm of filial piety as the strongest motivation to care. Reciprocity denied as a motivational factor.

Table 1b Meta-ethnography grid 2

Study ID Characteristics	Donovan & Williams, 2015	Han et al., 2008	Browne Sehy, 1998	Hinton et al., 2008	Ho et al., 2003	Jones et al., 2002	Jones et al., 2003	Holroyd, 2005	Kong et al., 2010
Sample	18 Vietnamese-Canadian caregivers; different relationship types	24 Korean American caregivers; different relationship types	10 spousal carers of Caucasian, Hispanic or Asian origin	9 Vietnamese carers; different relationship types	12 Chinese-Canadian caregivers; different relationship types	22 Chinese American and 19 Filipino American caregivers; daughters- or daughters-in-law	22 Chinese American and 19 Filipino American caregivers; daughters- or daughters-in-law	20 Chinese spousal caregivers	10 Korean caregivers; mainly daughters or daughters-in-law
Data collection	Longitudinal, one-to-one semi-structured interviews	Cross-sectional, face-to-face, semi-structured focus groups	Longitudinal, face-to-face and one-to-one semi-structured interviews	Cross-sectional, semi-structured interviews	Cross-sectional, face-to-face semi-structured interviews	Cross-sectional, face-to-face, one-to-one semi-structured interviews	Cross-sectional, face-to-face, one-to-one semi-structured interviews	Cross-sectional, face-to-face and one-to-one unstructured interviews	Longitudinal, face-to-face and one-to-one semi-structured interviews
Setting	NR	A community location (e.g. senior centre, community centre)	Participant's home	NR	Participants' homes, Chinese centre for geriatric care, participant's office	Informants' homes, the office of the research project, or other places selected by the caregivers	Informants' homes, the office of the research project, or other places selected by the caregivers	Main room of the family home, in most interviews the dependant husband was within earshot of the interview	Informants' home, churches, informant-owned workplaces
Methodology and method of analysis	Case study design; Values and emotions coding	NR; Thematic analysis/Qualitative content analysis	Qualitative descriptive design; An	NR; Thematic coding combined with a deductive coding	NR; Thematic analysis	Grounded theory; Grounded theory analysis	Grounded theory; Grounded theory analysis	Ethnographic approach; Constant	Descriptive qualitative; Qualitative content analysis

			interpretive reading guide					comparative method	
Study design	Longitudinal	Cross-sectional	Longitudinal	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Longitudinal
Country	Canada	The USA	The USA	The USA	Canada	The USA	The USA	China	The USA
Key concepts									
Cultural duty and beliefs of obligation	A duty to care for ill parents in Vietnamese culture.	Social expectations to assume the role, especially for the oldest son, daughter-in-law and women.	'Religion and culture that were influential, if not central, as a milieu within which caregivers made difficult decisions in moral conflicts.'	Spiritual and religious motivations viewed as reinforcing the core cultural duty arising from filial piety and respect toward the care recipient.	'The obligation to provide care that their traditional cultural values had instilled in them.' 'A sense of responsibility irrespective of their relationship to the care recipient.'	A sense of obligation, filial responsibility – as part respect for parents ingrained in cultural values.	'Commitment to the caregiving role was strongly rooted in the value system. They described an intense need to fulfil their filial obligation.'	Duty to one's husband to provide him with care - conflict between women's increasing awareness of their own needs what lead to the feelings of being compelled to care.	Caregiving as an obligation of the traditional Korean culture (Confucianism). Social expectations of caregiving (self-conscious", "face-saving") upholding duty to care.
Repayment motive	N/A	Repayment is mentioned.	Reciprocity and mutual obligations.	N/A	N/A	'Grateful for the love and care their parents had given them earlier, they wanted to "give back."	A sense of gratitude toward their parents and a desire to give back.	Reciprocity underpinned by a Confucian sense of duty in Chinese society limited in a modern world – 'whatever husbands had given them in the past had run out and was not enough to	N/A

								sustain current caregiving’.	
Gendered cultural expectations	Caregiving defines what it means to be a Vietnamese woman (‘being a Vietnamese woman’).	N/A	N/A	N/A	N/A	N/A	gender roles of mother, daughter, and wife	‘Engendered and generational expectations of marital obligations are supported by current government policy.’ ‘Social expectations of caring for a husband until he dies.’	N/A
Religious and philosophical ideas	N/A	N/A	N/A	Caregiving constitutes a ‘way of appeasing the ancestors and gaining their blessings and approval.’ Caregiving sacrifice (*hy sinh*) as another motive (it can be related to Christ's sacrifice or acts of compassion in Mahayana school of Buddhism).	Adherence to Chinese cultural and philosophical ‘standards’ – caregiving as a filial responsibility.	‘Spirituality was frequently reported as a personal resource.’	‘Inspired by compassion.’ (reference to Buddhism)	N/A	N/A

				Karma and afterlife.					
Filial piety	Caring as a reflection of one’s implicit value system.	Traditional cultural values of filial piety (Hyo).	N/A	‘Caregivers often described their own motivation for caregiving in terms of filial respect and piety (*có hiếu*), a key idiom and value that reflects the strong hold of Confucianism on Vietnamese culture.’	The value of filial piety implicitly seen in the caregiver account.	N/A	N/A	N/A	“Family and filial piety” – ‘the symbols of filial piety included respect, repayment, taking care of parents at home, and not sending parents to nursing homes.’
Shaping cultural identity	Value of caring ingrained in people’s identity.	N/A	N/A	Caregiving experienced in upbringing – observing caregiving in families as a preparation for the future role.	‘Anticipating the caregiver role as a result of filial obligation.’	‘Role modelling by the caregiver’s mother or grandmother in caring for family elders influenced the caregiver’s commitment to caregiving.’	N/A	‘Wives’ caregiving may be deeply internalized.’ Creation of self-identity of a caregiving married wife.	N/A
Rising demands of the contemporary world	N/A	Harsh immigrant life. ‘A struggle to hold of the traditional value of filial piety (Hyo) in American culture while working hard at the same time.’	N/A	N/A	N/A	Competing demands associated with their multiple roles.	Competing role demands (being a mother, grandmother, daughter and wife) related to combing different role duties.	N/A	N/A
Familism and family- and	N/A	Ambivalent about the use of formal services	N/A	N/A	‘They felt obliged to	N/A	Formal placement of the care	N/A	Familism (‘the symbols of

community-based care		as the family-based care is expected of the relatives.			provide care simply because they belonged to the same family.' Family care was praised over the institutional care.		recipient regarded negatively as caregiving is a family (filial) responsibility.		Korean family typically consisted of blood, love, marriage, and strong ties').
Love and emotional attachments	Expression of love.	N/A	Love for the care recipient.	N/A	N/A	'Some caregivers felt strongly that it was basic human love and not culture that motivated them to take on the caregiving role.'	N/A	N/A	N/A
Explanation (second-order interpretation)	Implicit cultural value system is foundational for the innermost motivations to provide informal care ingrained in the socialisation process – caregiving is an expected career/duty for women.	Motivations to care based are on traditional cultural values (Hyo) and social expectations grounded in them, even in the transnational context. influence of an American culture on cultivated traditional values creates contradictory motives around caregiving.	Religious and cultural beliefs that fostered a sense of moral obligation underlying motivation to provide care for the spouse or partner.	Spiritual and religious motivations shaped during socialisation viewed as reinforcing the cultural value of filial piety.	Motivation to assume a caregiver role and to continue with caregiving were based on normative cultural expectations. A sense of responsibility, anticipation of the role and familism as key components of motivations.	A strong sense of responsibility inherent in the transplanted filial values conveyed through the role modelling helps to sustain the caregiver motivations / to persist in the caregiving role.	Motivations to provide care deriving from determination to be loyal to the traditional culture upholding a strong system of filial values, especially among women, even on immigration (when adapting to a new culture).	Motivations to provide care ingrained in cultural models including: marital duty-bound roles, limited reciprocity public guidelines for married Chinese wives, the creation of self-identity through caregiving.	The traditional Korean culture dictated the norms of informal care provision: obligation to care based on the value of filial piety.

Table 1c Meta-ethnography grid 3

Study ID Characteristics	Mendez-Luck & Anthony, 2016	Meyer et al., 2015	Mok et al., 2003	Qadir et al., 2013	Muoghalu & Jegede, 2010	Yeo et al., 2002	Zhang & Lee, 2019	Harris & Long, 1999	Hsueh et al., 2008
Sample	44 female Mexican-origin caregivers, different relationship types	10 Vietnamese caregivers; mainly adult children	24 Chinese caregivers; mainly spouses	12 Pakistani caregivers; different relationship types	10 African caregivers	9 Vietnamese American caregivers; different relationship types	5 Chinese caregivers; different relationship types	15 Japanese and 30 American caregivers; husbands or sons	21 Chinese caregivers; mainly daughters or daughters-in-law
Data collection	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews and focus groups (which followed the individual interviews)	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews	NR	Cross-sectional, face-to-face semi-structured interviews	Cross-sectional, face-to-face unstructured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face semi-structured focus groups (2) and face-to-face, one-to-one semi-structured interviews (14)
Setting	Participants' homes or locations of their choice, such as a community center, coffee shop, or church	Mainly at participant's home	Informants' homes or the hospital clinic	Hospital settings	NR	Caregivers' homes	Home of the family caregiver	Homes or offices, the researcher's university office, restaurants and libraries	A private room at a church or at the participant's home

Methodology and method of analysis	Grounded theory approach; Constant comparative method	NR; NC (Grounded theory analysis)	Grounded theory approach; Constant comparison analysis	NR	NR	NR; Content analysis	Hermeneutic phenomenological approach; Phenomenological hermeneutic analysis	NR; NC ('Cross-cultural analysis')	NR; NC (Thematic analysis)
Study design	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	NR	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional
Country	The USA	The USA	China	Pakistan	Nigeria	The USA	China	Japan and the USA	The USA
Key concepts									
Cultural duty and beliefs of obligation	'The majority of all study participants did not view caregiving as an obligation but as a duty, responsibility, or commitment toward their family members' (commitment involved willingness to give care whereas obligation did not).	Filial piety as a deeply ingrained obligation based on a traditional cultural norm.	'Felt duty to care for the terminally ill individual.' 'A sense of obligation, affected the caregivers' willingness to care.'	'An obligation for them. It was called "sa'adat" (a sign of good fortune) and "sawab ka kaam" (virtuous deed).'	Obligation - caring for sick blood relatives is guaranteed. 'Cultural practices that enhance care for the sick in this area includes cultural obligations to the sick, affinity to blood relations, strong marital bond, and communal ownership of children.'	The duty and obligation – shaped by traditional cultural values, such as filial piety and ancestor worship, which are at the core of Vietnamese culture.	Obligation to provide care deeply rooted in the caregivers' innermost life goals, values, and moral principles (values of filial piety and familism).	Japanese sons' motivation - Son's place in the family structure (eldest sons) and an obligation to their parent based upon the notion of filial piety (and the availability of the daughter-in-law). American sons' motivation - a sense of duty based on a moral commitment, which was sometimes combined with a sense of love. Japanese husbands' motivation - a	The rule of primogeniture was broken in a different cultural setting (Chinse in the USA). More daughters than sons and daughters-in-law felt obliged to become the primary caregivers.

								sense of spousal obligation. American husbands’ motivation - sspousal obligation combined with a repayment motive and feelings of love.	
Repayment motive	‘To repay their family members for past contributions.’	A sense of reciprocity or way to give back to parents.	A sense of repayment.	‘Some respondents also believed that it is a reciprocal procedure, where one who cared for his/her parents will be rewarded with blessings of prosperity and success.’	N/A	A sense of delayed reciprocity.	A desire to repay the stroke survivors.	N/A	A sense of payback.
Gendered cultural expectations	Caregiving delegated to women due to the cultural value of marianismo.	N/A	N/A	‘Caring is traditionally considered women’s responsibility.’	‘Females are more willing to care for spouses living with HIV/AIDS than males.’	‘Traditional Vietnamese gender roles dictate women are the primary caregivers to disabled older adults, the reality “on-the-ground” is that this does not always occur.’	N/A	‘There is little cultural expectation for American sons that they become the caregivers, since it is most often seen as a women's role. Thus, an American son's decision to take on this role contradicts societal expectations.’	The rule of gender seemed to play a lesser part for the Chinese in the USA.

Religious and philosophical ideas	N/A	N/A	N/A	‘Religion (Islam) is an integral part of their lives. It determines their values and belief system. They believed that the disease is decreed by God. It is therefore a religious obligation to care for the older adults relatives and, hence, to be worthy of divine reward.’	Familial obligation rooted in religious beliefs (related to religious beliefs in ancestors).	N/A	N/A	N/A	N/A
Filial piety	N/A	‘Most participants acknowledged hiếu or filial piety as a motive for caregiving.’	‘The value of the dying person to the caregiver, the cultural concept of yi (rightness and responsibility), and filial duty were salient in this study.’	N/A	N/A	Filial piety as the basic cultural value shaping caregiving motivation.	Confucian notions of “family harmony” and “filial piety”.	Cultural values mentioned by Japanese carers.	‘Collectivism-based filial values that regulated conventional-reciprocal-filial obligations.’ ‘Acculturation has influenced and modified the traditional Chinese filial values.’
Shaping cultural identity	Culture-specific socialization informed by marianismo, a traditional gender role in the Mexican family based on the emulation of the Virgin Mary in the Catholic religion (“self-	N/A	Caregiving constituted an important part of a carer’s identity. ‘Realization that caregiving was CGs’ main motivation and purpose for living.’	N/A	N/A	N/A	Caregiving became a way to support each other as a family and a natural part of seeing oneself and their role in life.	‘Culture matters in the social shaping of the caregiving experiences of Japanese and American men through ideas, values, and assumptions.’	Upholding the identity and cultural values transmitted to next generations. ‘Accepting new cultural values does not necessarily mean

	sacrificing mother”).		‘In Confucian thought, the role of the self is not to express and manifest itself, as in Western models, but to develop the internal moral self. ‘							discarding old cultural values.’
Rising demands of the contemporary world	N/A	N/A	N/A	‘The rapidly changing social and economic environment is putting strain on the joint family caregiving system.’	N/A	N/A	N/A	N/A	N/A
Familism and family- and community-based care	N/A	Caregiving as a familial obligation - ‘Placing a loved one in a nursing home was an “American” thing to do and went against the values of respecting and honoring elders in Vietnamese culture.’	Familism (family-oriented achievement caring goals, familial self).	‘Families who opted for institutionalization were considered as (unlucky), (ill-fated), and (sinful).’	‘The traditional care system is such that it is the community and the family that care for the sick in every sense of the word.’ ‘The entire family is involved in caring for the sick.’	Caregiving is family-based, nursing homes should be avoided at any cost.	Familism. ‘Care and support the caregivers received from other family members helped them get through the hard times during caregiving.’	N/A	N/A
Love and emotional attachments	‘To show love and affection for their family members.’	Motivated to care out of love and affection.	‘A way of showing love to their relatives.’	N/A	N/A	N/A	Love, emotional attachment (adult–child caregivers’ love to their parents or the affection	Love mentioned by American carers.	‘Love appeared to be a major driving force for participants who brought elders

							between husband and wife).		into their family’s lives.’
Explanation (second-order interpretation)	A cultural value of marianismo informed motivations to provide care described as an inner duty or responsibility among Mexican-origin women.	Filial piety was most influential motivational factor in caregiving.	Confucian concepts of yi (appropriateness or rightness), and filial duty are strongly reflected in caregiving motivations.	Changing social and economic environment in Pakistan (developing country) is putting strain on the traditional familial model of caregiving based on cultural and religious values.	Communal caregiving responsibility comprises the key motivation to provide care. It is considered a cultural practice rooted in religious beliefs.	The sense of obligation for family members to care for elders shaped by traditional cultural and religious values altogether with the family-centred model of caring as the motivations for caregiving.	Motivation to care was interpreted as an obligation, affected deeply by the Chinese culture, described as a natural role one assumes when the need arises.	Japanese sons’ motivation to care derives mainly from cultural norms and social expectations; American sons’ motives revolve around personal, moral commitments. There were similarities between Japanese and American husbands’ motivations even though unlike the Japanese, in American culture there is a higher expectation for spouses to care for one another (social change in Japan).	Chinese carers living in the USA were motivated by a sense of obligation and payback, meeting personal and cultural values, while negotiating their old cultural norms and values.

Table 1d Meta-ethnography grid 4

Study ID **Characteristics**	**Kao & Stuifbergen, 1999**	**Kietzman et al., 2013**	**Lee et al., 2019**	**Leichtentritt et al., 2004**	**Ng et al., 2016**	**Park, 2012**	**Park, 2015**	**Qiu et al., 2018**	**Sasat, 1998**	**Sheu, 1997**
Sample	9 Taiwanese caregivers; adult children and spouses	42 caregivers of White, Latino, African American or Asian/ Pacific Islander origin; different relationship types	9 Korean caregivers; different relationship types	18 Arab-Moslem caregivers; different relationship types	20 mainly Singaporean caregivers; different relationship types	6 Korean American caregivers; different relationship types	Key Korean documents relating to filial piety and personal consultations with key informants involved in the legislative process	25 Chinese caregivers; adult children and spouses	44 Thai caregivers; different relationship types	16 Chinese-American caregivers; adult children
Data collection	Cross-sectional, face-to-face, one-to-one semi-structured interviews	Cross-sectional, telephone, one-to-one semi-structured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face and joint (family) semi-structured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Key documents in Korean social policy (Act on the Encouragement and Support of Filial Piety and other related laws)	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews	Cross-sectional, face-to-face and one-to-one semi-structured interviews
Setting	Nursing homes	NR	Participants' house, a cafe near their house, or a meeting room at a school	A caregiver-elderly joined house or a carer's house (in some cases a care recipient was in the same room as	Hospital	'Locations requested by each participant'	N/A	The participant's home and an office room provided by the hospital	Carers' own homes	Convalescent center, participants' homes

				the carer during an interview)						
Methodology and method of analysis	NR; Content analysis	Constructivist grounded theory approach; Grounded theory analysis	Ethnographic approach; Inductive content analysis	Hermeneutic phenomenological approach; Hermeneutic phenomenological analysis	NR; Thematic analysis	Interpretive phenomenological approach; Thematic analysis	Qualitative documentary research; Thematic analysis mixed with a chronological narrative	Qualitative descriptive; Content analysis	NR; NC (Narrative analysis)	Grounded theory; Constant comparative analysis (with Clarke's reframing of grounded theory analysis)
Study design	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional	Cross-sectional
Country	Taiwan	The USA	South Korea	Israel	Singapore	The USA	New Zealand (but the study pertains to Korea)	China	The UK	The USA
Key concepts										
Cultural duty and beliefs of obligation	Strong cultural filial values (eldest son or daughter-in-law providing care - the responsibility of the adult children) which are related to a sense of obligation (feeling of responsibility).	‘Perceptions of Choice (obligation) vary by the context of the caregiver's experience, which includes the influence of cultural and gender norms, as well as situational factors; having no	Sense of responsibility and/or an imposed duty to care. ‘Some participants took the duty of caregiving for granted. In particular, they accepted and assumed the duty of supporting old parents,	A strong sense of motivation and commitment for following the Islamic traditions, family and social values (doing the “right thing”).	‘Personal value was often expressed in terms of filial piety or family obligation, a culturally valued trait in Singapore.’ ‘Because there was simply ‘no one else’. The decision to	Obligation based on adult children’s adapting the Confucian-inspired notion of filial piety.	Implicit lawful obligation – ‘This symbolic law sends a declaratory message that the government continues to make efforts to maintain the tradition of filial piety as the key aspect of family relationships and the foundation for	‘Responsibility and obligation play significant roles in marriage.’ ‘Adult-child caregivers are influenced by Confucian ideology of filial piety’ – caregiving is an obligation.	Spouse carers - marital commitment. Younger caregiving relative group - family responsibility/filial duty. ‘The responsibility for care is most likely to fall on the youngest child, who would be the last to marry.’	Obligation to provide care regulated by cultural norms: birth order (different expectations depending on this), child's age (the oldest son), gender and marriage – after a marriage it’s daughter-in-law’s

		choice; being purely volitional; taking control; or simply, being a “given.”	assigned to the oldest son and his wife, which is part of Korea’s traditional culture.’		care was mainly due to concrete circumstantial factors rather than internalized social expectations of duty.’		the rest of society.’			responsibility (if there is any.)
Repayment motive	N/A	N/A	Caregivers ‘wanted to return the love they got from the patients.’	‘Reward was discussed on a concrete level while referring to one’s own elderly days when s/he will need help and assistance from family members.’	N/A	N/A	N/A	‘Caregivers look after care recipients because they feel grateful for the care and love they previously received from those care recipients.’	‘The sense of reciprocity or concept of parent repayment refers directly to the obligation to repay parents and is a value firmly ingrained in the culture which is equivalent to 'kathanyu katawethi' in the Thai context.’	‘The assistance provided between parent and child can be characterized as reciprocal.’
Gendered cultural expectations	N/A	Caregiving as a ‘woman’s work.’	N/A	‘The Israeli Moslems’ traditional gender roles and norms of primogeniture have led to several group norms. If the elder with dementia was female (regardless of her	N/A	N/A	N/A	N/A	Caregiving a women’s job (especially the youngest daughter); belief that a female could provide better care than a male.	N/A

				marital status), the last daughter-in-law was expected to be the primary caregiver. If the elder was male and a widower, then caregiving by the daughter-in-law was also expected. If the elder was male and married, then his wife was expected to be the primary caregiver, especially for personal care.’						
Religious and philosophical ideas	Religious beliefs – karma; philosophical beliefs - benevolence (rooted in Confucianism).	N/A	N/A	Caregiving as upholding social, family, and religion traditions. ‘Informants believed God would reward them.’	‘The recognition that fellow human beings ought to be cared for and teachings from personal faiths and religions.’	N/A	‘The underlying principle of this law is based on not only the continuing Confucian and Buddhist heritage but also the Christian model of family love and attachment. This cross-religion approach of family responsibility	‘One’s ancestors and the Buddha are symbols of power beyond humanity, and they help caregivers cope with and manage difficult times and emotional burdens.’	Buddhist doctrine of reciprocity (Karma) – ‘Repaying parents gives satisfaction in fulfilling the obligation imposed by Buddhist doctrine.’	Religious beliefs, e.g. Kharma. “Some Chinese parents say that "they owed their children in their previous life, so now baby is coming back to ask for returning the debt."

							serves to uphold the people’s common concern for filial piety and affirms the validity of traditional filial practices.’			
Filial piety	N/A	N/A	Traditional Korean values (Confucian-based Asian nations).	N/A	‘Filial piety was discussed as a social expectation rather than as a personal value.’	‘Confucian-inspired notion of filial piety informing the social and personal obligation to care.’	N/A	A value of filial piety.	A value of filial piety.	Filial piety (Being Hsiao): - to be nice to your parents, to please your parents and care for them; - Shun (obedience) and Ti-Hwa (listening to parents), to follow the elderly's will and respect their way of doing things; - not to put shame on parents and bring honour to them.
Shaping cultural identity	N/A	N/A	It was noted that for some carers it was	N/A	N/A	N/A	Incorporation of Korean	‘The commitment of caregivers	N/A	‘The concept of Hsiao was conveyed to

			an expected part of their life due to cultural norms of providing care (oldest son or daughter-in-law is already brought up knowing they would have to provide care to their parents when they are old).				values within socialization - ‘Educational purpose for family support or responsibility – to encourage filial responsibility that serves to remind all of what core Korean values are.’	to caregiving is significantly influenced by the role model set by their grandparents or parents in looking after family elders. This perception is deeply rooted in Chinese culture, arising “naturally” without conscious thought.’		them through socialization, i.e. school education, family participatory teaching and parental demonstration, as well as various media of oral transmission and rituals from the public community.’
Rising demands of the contemporary world	‘Children caregivers often reported a conflict between caregiving to the elder and responsibility to their own nuclear family and business.’	N/A	N/A	N/A	‘Negotiating other life roles (including professional life and activities around constraints of illness and caregiving).’	N/A	N/A	N/A	N/A	Rising and competing role conflicts.
Familism and family- and community-based care	Care is family-based accordingly to the cultural norms. Additionally, negative public opinion toward institutionalization	N/A	Caregiving is oriented towards the oldest son and his wife who are deemed responsible	‘Social norm that would expect care for disabled elders to remain predominantly within the family.’	N/A	N/A	N/A	‘Caregiving is a culturally prescribed obligation within family relationships.’	Care should be provided at home.	Family-based caregiving.

	restrained caregivers from utilisation of formal support.		to care for aged parents. High familism.							
Love and emotional attachments	N/A	N/A	N/A	N/A	love, loyalty	N/A	N/A	N/A	N/A	(Showing) affection and love
Explanation (second-order interpretation)	Strong cultural filial values related to the feelings of responsibility and religious and philosophical beliefs around caregiving.	Caregiver perceptions of choice in assuming the caregiver role reflect existing cultural and gender norms, as well as practical circumstances.	Participants regarded the responsibility of caring as a main motive for caregiving. In this study, the oldest son and/or his wife demonstrated a higher willingness to provide care than other relatives.	Caregiving motivations are informed by Islamic cultural norms, family and social values.	Caregivers reported a range of motivations underpinning their decision to provide care: personal values (expressed in terms of filial piety or family obligation); religious beliefs; social expectations; perceived lack of choice or alternatives. Filial piety was understood either as a personal value (more an 'own' value and intrinsic	Confucian-inspired notion of filial piety informed the social and personal obligation to provide informal care.	Filial piety is considered as a cultural value and the process/act of giving care itself. It is incorporated in carers' socialisation and comprises an implicit obligation of adult children to provide care for their elderly parents.	A strong sense of responsibility, reciprocity and filial commitment (which originated from filial values such as filial piety) were the main motivations of caregivers to carry on with their roles in caregiving.	The primary motivation to care was derived from: fulfilling the expected cultural norm of filial obligation, fulfilling a desire to reciprocate for past services, and building up future merit for the caregiver (Buddhist beliefs).	Hsiao (filial piety) was a central belief and a cultural blueprint incorporated through socialisation and upheld by cultural norms that oriented adult children's caregiving ensuring the maintenance of traditional value of caregiving. The normative belief system of Hsiao continued to influence filial behaviour even after social and economic changes.

					motivation) or a social expectation (more a 'cultural' value; or 'a more externally oriented motivation').					

B7 Appendix - CASP qualitative checklist for the meta-ethnography demonstrating how each study addressed the CASP qualitative checklist (2014) quality aspects

Study	**CASP Checklist Questions**										**Methodological quality summary**
	1 Was there a clear statement of the aims of the research?	2 Is a qualitative methodology appropriate?	3 Was the research design appropriate to address the aims of the research?	4 Was the recruitment strategy appropriate to the aims of the research?	5 Was the data collected in a way that addressed the research issue?	6 Has the relationship between researcher and participants been adequately considered?	7 Have ethical issues been taken into consideration?	8 Was the data analysis sufficiently rigorous?	9 Is there a clear statement of findings?	10 How valuable is the research?	
Globerman (1996)	?	✓	✓	✓	✓	✓	?	✓	✓	✓	High
Yamamoto and Wallhagen (1997)	✓	✓	✓	✓	?	?	?	✓	✓	✓	Moderate
Sheu (1997)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
Browne Sehy (1998)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Sasat (1998)	✓	✓	✓	✓	✓	?	✓	?	?	?	Moderate
Harris and Long (1999)	✓	✓	✓	✓	✓	?	?	✗	✓	✓	Moderate
Kao and Stuifbergen (1999)	✓	✓	✓	✓	✓	?	?	?	✓	✓	Moderate
Chao and Roth (2000)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Kim and Theis (2000)	✓	✓	✓	✓	✓	?	?	?	?	?	Moderate
Van Sjaak Geest (2002)	✓	✓	✓	✗	?	✓	?	?	✓	✓	Moderate

Jones et al. (2002)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Yeo et al. (2002)	✓	✓	✓	✓	✓	?	?	?	✓	✓	Moderate
Jones et al. (2003)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Ho et al. (2003)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Spitzer et al. (2003)	✓	✓	✓	✓	✓	?	?	✗	✓	✓	Moderate
Mok et al. (2003)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Leichtentritt et al. (2004)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High
Holroyd (2005)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Wallhagen and Yamamoto-Mitani (2006)	✓	✓	✓	✓	?	?	?	✓	✓	✓	Moderate
Han et al. (2008)	✓	✓	✓	?	✓	?	✓	✓	✓	✓	High
Hinton et al. (2008)	✓	✓	✓	✓	✓	?	?	?	✓	✓	Moderate
Hsueh et al. (2008)	✓	✓	✓	✓	✓	✓	✓	?	✓	✓	High
Kong et al. (2010)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Muoghalu and Jegede (2010)	✓	✓	?	?	✓	?	?	?	✓	?	Moderate
Parveen et al. (2011)	✓	✓	✓	✓	✓	?	✓	✓	✓	✓	High
Park (2012)	?	✓	✓	✓	✓	✓	?	✗	✓	?	Moderate
Qadir et al. (2013)	✓	✓	✓	✓	✓	?	✓	✗	✓	✓	Moderate
Kietzman et al. (2013)	✓	✓	✓	✓	✓	?	?	✓	✓	✓	High

Donovan and Williams (2015)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Meyer et al. (2015)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Park (2015)	✓	✓	✓	**?**	**?**	**N/A**	✓	✓	✓	**?**	Moderate
Ng et al. (2016)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
van Wezel et al. (2016)	✓	✓	✓	✓	**?**	**?**	✓	**?**	✓	✓	Moderate
Mendez-Luck and Anthony (2016)	✓	✓	✓	✓	✓	**?**	✓	✓	**?**	**?**	Moderate
Qiu et al. (2018)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High
Zhang and Lee (2019)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	High
Lee et al. (2019)	✓	✓	✓	✓	✓	**?**	✓	✓	✓	✓	High

Key:
(✓) indicates that the study was assessed as possessing the specified quality aspect

(✕) indicates that the study was assessed as lacking the specified quality aspect

(**?**) indicates that it was not possible to sufficiently assess whether the study possesses the specified quality aspect

B8 Appendix - Detailed characteristics of included studies

A total sample of 833 caregivers participated in the included studies with one study focusing additionally on the analysis of documents underpinning the nation-specific social policy on informal caregiving [1]. Most participants were of Asian ethnic origins (N=574; 68%), followed by Caucasian ethnicity (N=90; 11%), non-Caucasian American ethnicity (N=80; 10%); Black African ethnicity (N=71; 9%) and Arab ethnicity as the smallest ethnic group within the studies synthesised (N=18; 2%). Many of the studies (N=33, 89%) included mixed caregiver-care recipient relationship types but generally the most common relationship types included adult children (including daughters-in-law) and spouses.

The study setting, i.e., where data was collected, was not reported in 7 of the studies, in one it was inapplicable (documentary study). In the remainder, various settings were described: caregivers' homes, hospital clinics and wards, the researcher's university office, support group centres, senior centres, community centres, churches, informant-owned workplaces, cafés and nursing homes.

In terms of methods of analysis, nine studies used grounded theory [2–10]; four applied varying methods of ethnographic analysis [11–14]. Twelve studies were descriptive in their approach using thematic or content analysis [15–26], one used a qualitative interpretive approach [27], one employed a case study design with 'values and emotions coding' stated as a method of analysis [28], one describes a 'cross-cultural analysis' [29], one involved qualitative documentary research where thematic analysis was mixed with a chronological narrative [1]; one applied a narrative analysis [30]. Three studies reported using phenomenological and/or hermeneutical methods of analysis [31–33]. Finally, the methodology and method of analysis of 3 qualitative studies were not specified [34–36]. Most studies used semi-structured interviews to collect data, except for one that used unstructured interviews [13] and two that combined both unstructured and semi-structured interviews [33,37].

Only four studies [3,19,21,28] applied longitudinal design. The authors of one study did not specify the research design [36], i.e. data collection was not described.

Amongst the included studies, 21 (57%) had no or very minor methodological concerns, whereas 16 (43%) were judged to be of moderate quality.

B9 Appendix - Meta-ethnography findings. A long draft version of qualitative findings

Six main concepts were identified from the analysis of cultural motivational determinants of informal caregiving, including: *cultural self-identity*, which was an overarching theme; *cultural duty and beliefs of obligation*; *cultural values; love and emotional attachments*; *repayment motives*; and *competing demands and roles*.

The generated concepts were interrelated and mutually reinforcing. Firstly, the six above-mentioned concepts are presented separately, beginning with the overarching concept of *cultural self-identity* and ending with *competing demands and roles.* Subsequently, the model of cultural underpinnings of caregiving motivations is presented to provide an overall integrated explanation of the concepts and the interactions between them.

Tables 2a & 2b below show the concepts and sub-concepts present in each of the included studies.

1. Cultural self-identity

A term 'cultural self-identity' refers to a caregiver's identity informed by their cultural background [43].[3]

1.1 Cultural self-identity

Caregiving constituted an important part of caregiver's identity which was either expressed directly by authors with a reference to identity [8] or an 'internalisation' of the caregiving role [13]. It was highlighted that being an informal caregiver was a natural part of seeing oneself and their role in life [8,33], especially being a woman [6,34]. Spitzer et al. [11] interpreted their participants' account stating that: 'As mothers of the nation and reproducers of society, [women are] entrusted with the task of maintaining cultural identity through educating the young and modeling their own [caregiving] behavior.' Indeed, the idea of maintaining the caregiving identity was strongly culturally informed (see the concept 'cultural values' below). For example, Mok et al. [8] discussed the role of the caregiver self as based on cultural grounds: 'In Confucian thought, the role of the self is not to express and manifest itself, as in Western models, but to develop the internal moral self.'

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[3] The term 'cultural self-identity' was applied rather than 'cultural identity' or 'ethnic identity'. The latter usually refers to an individual's ancestral geographic origin, whereas 'cultural identity' relates to culture(s) which is/are groups of people who share knowledge, beliefs, norms and behaviours (e.g., gay culture), but not necessarily the geographic origin (and thus ethnic identity may/may not be part of cultural identity; Unger, 2011). The term 'cultural self-identity' acknowledges that self-identity is formed as part of and informed by cultural identity, i.e. individual features of culture(s) is/are incorporated into the self-identity [49], for instance caregiver's self-identity (e.g., self-identified caregiver who sees themselves as influenced by Jewish culture and accordingly identifies as a Jewish caregiver/caregiver following Jewish cultural norms and expectations).

1.2 Cultural self-identity and socialisation

Cultural self-identity was shaped by caregiver socialisation. The examples refer to the role modelling by the caregiver's relatives in caring for family members, usually grandparents or parents in looking after family elders [4,6,17]**.**

1.3 Cultural values ingrained in socialisation

Culture-specific socialisation (role modelling by the caregiver's relatives in caring for family members even before someone becomes a caregiver) was informed by cultural values, described above (e.g., the value of 'marianismo' in Mexican culture or Confucianism in Asia) [6,16,29; see the concept 'cultural values' below). Park (2015) referred to the 'incorporation of values within socialization', some to the value of caregiving ingrained in people's identity [10,22,28]. These cultural values related to caregiving were said to be conveyed to individuals through different modes of socialisation, i.e. family participatory caregiving duties, school education and various media of oral transmission and rituals [10] - all as a preparation for the future role [22]. 'Only through internalization of caregiving values in one's identity, can the values be transmitted to next generation', Hsueh et al. [25] concluded on the relationship between cultural values, transgenerational socialisation.

1.4 The sense of preparedness and expectedness

Given that the cultural self-identity of the future caregiver was shaped in socialisation, informal care was often an expected part of an individual's life [14]**.** It comprised an expected career for Japanese caregivers, brought up with an expectation that either an unmarried adult son or – if married - his wife (daughter-in-law) will need to provide care to their elderly parents when such need arises. Social embeddedness of filial caregiving was taken for granted and cultural norms upheld it [3]**,** providing a sense of preparedness and expectedness (anticipation) of the role [23,37]**.** However, the relationship between the sense of preparedness/expectedness and the sense of acceptance of the role was not explored in any of these studies.

Even though the consideration of the impact that the cultural self-identity may have on caregiving motivations is absent in 43% of included studies (see Table 2a & b), the synthesis of translations clearly depicted – in our view - the identity as mediating between (i) the values one holds as well as the sociocultural norms to which one conforms and (ii) the sense of obligation and responsibility (the last section of findings describes the meta-ethnographic line of argument). A large number of included studies pertaining to transnational or migrant caregivers [4,5,7,10,11,15,16,19,20,22–25,28,30,32,34] interestingly confirm that the acculturation processes did not significantly change the cultural values as these were ingrained in caregiver's identity as part of socialisation – this preserves its solid foundation for the obligation(s) to provide care.

2. Cultural duty and obligation

2.1 Beliefs about obligation grounded in cultural norms

The concept of obligation was identified in all synthesised studies as one of the most overriding motivations for caregiving. The concepts of 'duty', 'obligation' or 'responsibility' were referred generally to an individual sense of obligation(s) as well as an objective obligation, both rooted in underlying cultural, societal, gender norms and religious and philosophical beliefs. The authors of the studies reviewed, however, did not make an explicit distinction between the sense of obligation and the obligation itself, perhaps because of the interrelated nature of both of them, with the first one being informed by the latter. In the sense of obligation an emphasis is placed on the perceived feelings of obligation or duty to provide care, whereas in the latter the term pertaining to obligation (or duty) is treated as synonymous to the cultural norms of providing informal care. There are numerous examples depicting this with a reference to a role played by the social hierarchy, birth order, caregiver's age, gender and marriage in determining who should become a caregiver: in Taiwan a married woman belongs to her husband's family and thus is obliged to assume a caregiving role - eldest son or daughter-in-law providing care [2,18]**;** in Ghana the caregiving responsibility goes first to children, and secondly to a married adult child [12]; in both the Turkish and Moroccan communities, family care is primarily handled by the eldest daughter or the wife of the eldest son [34]**;** in Korea the role is preserved for the oldest son or a daughter-in-law [14,20]; caregiving duty to one's husband is strongly grounded in Chinese culture [13]**;** in Nigeria caregiving is sustained via cultural obligations pertaining to the familial relationships, marital bonds, and communal ownership of children [36]**;** the family structure regulates Japanese adult children obligation to provide care to their parent (i.e. the availability of the eldest sons or the daughter-in-law) [10,29]**;** amongst British-Thai caregivers the caregiving duty was most likely to assumed by the youngest child, the last to marry [30]**.**

2.2 Gendered cultural expectations

The concept of gendered cultural expectations builds upon the layer of cultural norms. The concept refers to engendered expectations towards an individual based upon the existing cultural norms, i.e., traditional gender roles and/or norms of primogeniture, if present. In the studies synthesized it was common that the caregiving was seen as a women's domain / a women's role [2,6,9,11–13,24,25,27,29–31,34–37]. Even in cultures such as Japan or Korea in which it is the oldest son who is expected to provide care, the situation changes when the oldest son gets married as then the role should be assumed by the daughter-in-law [3,37]**.** The expectations play also an important role in caregiver socialisation [27,28], thus shaping cultural self-identity (a separate concept described later). For example, Donovan & Williams [28] showed in their study that informal caregiving comprised part of women's self-identity, i.e., being a Vietnamese woman implies the provision of care to family member(s) in such need, there is no distinction between a role of a caregiver and a role of a woman.

2.3 A sense of obligation upheld by social expectations

Cultural norms regulating the provision of informal care and underlying the sense of responsibility discerned as strong caregiving motives were upheld by social expectations [19,35]**,** lawful obligations [1] and could be modified by situational factors, e.g., presence/lack of alternative caring arrangements [9,26]**.** Kong et al. [19] described caregiving duty as "self-conscious" and "face-saving", whilst Yeo et al. [35] framed it as "a sign of good fortune" and "virtuous deed." These were important motivations for providing informal care.

2.4 Cultural value system as a latent level underpinning a sense of obligation

Some authors of the reviewed studies searched for the basis of the caregiver duty and obligation deeper than in the content of cultural norms which led to the assumption that cultural norms do not affect a sense of obligation directly. The link between the two was accented in a large number of studies [2,10,12–14,18,20,29,30,34,36] with 11 studies highlighting the factors underlying the sense of duty and obligation referred to the traditional cultural value system [4,5,23,31], with the specific indication of the Confucian-inspired value of filial piety (which comprises a separated concept) [7,10,17,24,32,33]**,** the values related to ancestor worship [24] or the value of familism [31,33]. Therefore, cultural values constituted a distal factor shaping caregiving motivations and underpinned cultural norms.

3. Cultural values

Cultural values comprised of three sub-concepts of *filial piety, familism* and *religious and philosophical ideas* which oriented around perceived cultural norms and underpinned the caregivers' perceived duty and obligation to provide care.

3.1 Filial piety

Filial piety, defined in lay language as respect for parents and the family elderly, was understood as a traditional cultural norm which engendered personal expectations for caregiving amongst adult caregivers caring for a parent and was discerned as a cultural value [2]. As mentioned in the previous paragraph, cultural values were identified as a distant and essential factor impacting motivations to provide care in 11 studies out of 37 that were synthesised in the meta-ethnography. The value of filial piety was represented in 57% of the studies and it could be hypothesised that its lack of identification in other studies did not decrease its importance in motivations to provide care as cultural values possibly played a vital role in caregiving motivations on an implicit/latent level [23]. Filial piety posited an 'inevitable responsibility' on adult children to provide care to their parents [2]. The notion was rooted in a concept of social debt in Confucianism and its symbols included: respect, repayment, providing care to parents at home, pleasing your parents, being obedient and respect their way of doing things, not putting shame on them, bringing honour to parents [10,19]. As stated by Hsueh et al. [25]: 'Collectivism-based filial values regulated conventional-reciprocal-filial obligations.' Authors of one of the papers [26] argued that filial piety acted more as an external expectation rather than personal value, however it is worth noting that cultural values could be distinguished from personal values. We propose this may be useful for two reasons: (a) there was variability in how individuals behaved with respect to their variety of values [39] and (b) the distinction between cultural and personal values seemed to be partly supported by the conceptualization introduced by one of the pioneers in the scientific study of values, Rokeach (1973). He described values either as individual or societal constructs, also with considerations of reciprocal relationship and fit between individual and supraindividual (i.e. cultural, institutional or group) value types [41]. The fit between the individual values and supraindividual is not always consistent and this issue may play a role in how filial piety influences motivations to provide care.

3.2 Familism, familial loyalty and solidarity

The cultural value of familism is a term used by the reviewers to embrace the second-order accounts that referred to 'strong identification and attachment of individuals with their families (nuclear and extended) and strong feelings of loyalty, reciprocity and solidarity among members of the same family' (Sabogal et al., 1987, p. 397–398), often implicitly expressed as a belief that care ought to be provided by family and family alone. Familism assumed and preserved the provision of informal care by family as this is seen as being 'loyal' to the family [11,19,23]. Kong et al. [19] described the symbols of the value of familism in Korean family as to be 'consisted of blood, love, marriage, and strong ties.' Mok et al. [8] reflected on familism by referring it to the 'familial self' of the caregivers whilst Qiu et al. [17] wrote about caregiving as a 'culturally prescribed obligation within family relationships.' The value of familism underlied a social norm that (a) expected care for care recipients to remain within the family (usually designated members of family) [31] and (b) institutionalisation or formal support should be avoided [7,16,18,23,24,30,31,34–36].

3.3 Religious and philosophical ideas

For some, religious ideas, related to different traditions of religion, were described as the reasons behind the provision of informal care and/or as a form of culturally-bound obligation or responsibility [16,23]. Religious and philosophical ideas (e.g., Confucianism in Asia highlighting the significance of filial piety, familial relationships or respect for elders) determined caregivers' values and belief system [35]. Religious and philosophical ideas, incorporated in cultural values and affirming them, comprised another determinant underlying personal and familial obligations to provide care [1].

4. Love and emotional attachments

Expression of love discerned behaviourally, and love and attachment as affections towards the care recipient, were identifiable motives for assuming the role and for continued caregiving, evidenced less frequently than previous concepts (in 43% of all studies included for the synthesis). Both were identifiable motives for assuming the caregiving role and for continued caregiving, i.e., caregiving provides the opportunity to demonstrate love behaviourally or emotionally. The distinction between the expression of love and the feelings of love demarcates the possible explanation of the phenomena. The former constituted an explicit way of showing love and affection to caregiver's relatives as prescribed by sociocultural norms and expectations, e.g., behaviour informed by filial piety or other cultural values [6,8,10,26,28]**.** The latter notion refers to emotional attachments, the feelings of love or affection towards a care recipient as motivators to start and to continue providing informal care [4,7,12,16,21,25,29,33,37]. It is worth noting that in two studies, love and affection were stated to be insignificant in terms of motivations to provide care [15,27].

5. Repayment and reciprocity

Repayment motive referred to the sense of reciprocity or duty to reciprocate the care and/or love the caregivers had previously received from care recipients, based on mutual obligations or a desire to repay by fulfilling the caring duty [2–4,7,8,10,14,17,20,21,24,25,31,33,37]. Repayment was informed either by cultural norms (e.g., care recipient's previous conduct prerequisite for receiving informal care) [12] or its sources may derive from cultural values and religious beliefs [6,13,30,34,35], for example a reciprocity was said to be underpinned by a Confucian sense of duty [13] or a way to gain blessings of prosperity and success from supernatural forces [35]. In contract, authors of one study [15] highlighted that caregivers denied considering a repayment as a motive for their caregiving.

6. Competing demands and roles

6.1 Changing economy and societal environment

The rapidly changing economic and societal environment shaped motivations and willingness to provide care as seen in the accounts contained within reviewed studies. Although the concept of rising demands was the least evidenced, i.e. in a quarter of the synthesized studies (27%), competing demands pertaining to caregivers' increasing contribution to the labour market, the perceived and actual demands of professional work, employment migration and variable access to/costs of care and support to facilitate continued paid employment were stated to be putting strain on the traditional family caregiving systems, influencing motivations and willingness to initially provide care and to continue doing it, mostly negatively [35,37]**.** Spitzer et al. [11] noted that employment did not offer flexible hours, supplemental health insurance or family benefits and it was difficult for caregivers to combine the caregiving role with the demands of a professional work. Similar interpretation of this phenomena was provided by Kim & Theis [15] who related this to a notion of a ‘life in a different society and new area.’ This highlights the importance of the impact of flexible employment policies and practices (e.g., flexible hours) on caregivers as seen in some evidence, e.g, that greater flexible work practices increase support for combining caregiving and paid employment [44–46]. As can be seen, these competing demands were stated to influence motivations and willingness to provide care mostly negatively. Observations as to whether such factors have any positive impact were absent in the reviewed literature.

6.2 Competing demands and roles

The competing multiple roles that some caregivers occupied negatively influenced motivations and willingness to initially and continuously provide care [4,18]. Being a mother, grandmother, daughter and wife and at the same time a being employed outside the caregiving role were reported as the most challenging instances for the motivations to start and continue with caregiving [20,24]**.** Rising and competing role conflicts had a significant impact on the caregiving experience [10,26]**.**

Role discrepancies can be discerned in the light of caregiver conflicts between competing identities, for instance, between being a caregiver, mother/father, daughter/son, wife/husband and employee. Given that the cultural self-identity of an informal caregiver is strongly rooted in cultural values and religious beliefs and that the rising demands of the economic world often led to informal caregivers being employed apart their caregiving duties, an inconsistency between the roles may be a substantial factor influencing motivation and willingness to provide informal care. The strain described in the synthesised studies [35,37] may have been be source of tension if important cultural values were being challenged and negotiated. Identity inconsistency between different roles may challenge identity, resulting in stress or initiating a transition to a different role (e.g., relinquishing employment; [47]) or renegotiation of cultural values and norms (e.g., a caregiver of the opposite sex to the care recipient provides informal care which was previously considered culturally inappropriate and unacceptable to both).

Model of cultural underpinnings for motivations to provide care

The concepts (1-6) described above informed a meta-ethnographic line of argument, explaining how cultural norms and values influenced overall motivations to provide care (see Figure 1).

The concepts served to develop a meta-ethnographic line of argument (see Table 1), explaining how the cultural norms and values potentially influence motivations with the cultural self-identity posited as a central concept of the argument. The Table 1 relating to the line of argument shows the reviewers' interpretations (third-order constructs) and authors' interpretations (second-order constructs) across all studies. A model, based on these findings from across the papers, was also presented as pyramid chart (see Figure 1).

The model posits that explicit personal motives pertaining to *the sense of cultural duty and obligation to provide care* (2), *the expression of love and emotional attachments* (4) and *the desire to repay/reciprocate the care recipient* (5), constructed during socialisation, are sustained by distal but underpinning factors, i.e., the *caregiver's cultural self-identity* (1) and the *culture-specific care norms and cultural values* (3) (filial piety, familism, and religious and philosophical beliefs); and balanced against potential barriers created by *competing demands* (6). The perceived cultural duty and obligation to provide care (2), described as the overriding motivation for caregiving, is strongly determined by cultural factors such as cultural values (3) which were mainly described as implicit, latent factors [3,5,23–25,27,30–33,7,8,12,14–17,22], positioned as distal influences on motivations to provide care (see Figure 2).

The developed model of the cultural underpinnings for motivations for providing informal care posits the sense of obligation, i.e., perceived feelings of obligation or duty to provide care, as constructed during socialisation and sustained by the caregiver cultural self-identity. The sense of obligation, altogether with the expression of love and emotional attachments as well as a desire to repay the care recipient have their sources in culture-specific norms of providing care and cultural values encompassing the values of filial piety and familism, and religious/philosophical beliefs. The concept focused on cultural self-identity is central to the model as it translates the foundational cultural norms, values and beliefs to the sense of obligation to provide informal care, regulating also the expression of love and a desire to repay - stated as other caregiving motives. Cultural values and norms of providing care had to be internalised to guarantee the sustainability of the most apparent motivations and willingness for providing care, i.e., the sustainability of caregiving motivations is warranted to a large extent by caregiver cultural self-identity. The model is novel in a way that it presents how the conceptualised levels pertaining to determinants of caregiver motivations interact and build upon each other (see Figure 1). The obligation to provide care, described as the most obvious motivation for caregiving, can be seen as a tip of the iceberg that is strongly determined by distant or latent cultural factors such as cultural values or religious and philosophical ideas which were mainly provided as implicit factors in the studies synthesised [1,2,7,8,10,11,16,18,19,23–26,30,31,34–36,39], positioned unsurprisingly as distant factors influencing motivations to provide care. An interesting exception comprises a sub-concept of the value of filial piety, based on which the authors made more direct links between the value and motivations to caring, drawing on the examples where the value is even sanctioned as a lawful obligation (Korean Act). The meta-ethnographic line of argument also highlights the central and crucial role of self-identity in informal caregiver motivations and willingness to provide care.

Based on the model, it might be expected that future informal care provision would be secured by being strongly ingrained in culture, and cultural self-identity. However, key factors may modify the salience of culture in determining caregiver motivations: (a) the notion of perceived choice in undertaking the role, i.e., when considering caregiving duty and obligation; (b) competing demands, roles and identities; (c) the consideration of care home placement which demonstrated that cultural values can be negotiated (in one study; Ho et al., 2003),; (d) other contextual factors not discussed in the reviewed studies but seen in other studies of caregiver motivations (e.g., the stage and severity of a care recipient's illness, caregiver's life stage, family structure, geographical distance between the care recipient and caregiver; e.g., Bei et al., 2021). Additionally, even though cultural values around caregiving were strongly rooted and seen to have a vital role in shaping motivations for caregiving, the boundaries of understanding what caregiving should entail (as prescribed by the cultural values) may change in the face of transitions in the care recipient's experience. For example, admission to a care home may offer the caregiver a different way of caring for someone rather than an opportunity to relinquish the caregiving role.

Table 1 A meta-ethnographic line of argument

Concepts	**Second-order interpretations**	**Third-order interpretations**
Cultural duty and beliefs of obligation	(a) Obligation(s) to provide care is the most overriding motivation for caregiving, underpinned by cultural, societal and gender norms of informal care provision, a cultural value system and cultural beliefs.	(f) The sense of obligation, i.e. perceived feelings of obligation or duty to provide care, is developed during socialisation and sustained by the caregiver cultural identity.
Cultural values	(b) Cultural values of filial piety and familism and religious/philosophical beliefs underly the sociocultural norms for providing informal care.	(c) Cultural values regulate caregiver perceived and objective obligations.
Cultural self-identity	(d) Caregiving constitutes an important part of caregiver's identity, shaped in culture-specific socialisation (including incorporation of caregiving values), often making informal care an expected part of an individual's life.	(e) The sense of preparedness/expectedness is one of the components of caregiver identity. Caregiver cultural identity is central and critical to sustain motivations and willingness for providing care.
Love and emotional attachments	(h) Love, attachment and affections towards the care recipient as well as showing love to care recipient are additional motives for caregiving.	(i) Showing love and affection is distinguished from the feelings of love with the former being prescribed by sociocultural norms and expectations.
Repayment motives	(g) The sense of reciprocity/repayment or duty to reciprocate are influenced by cultural norms or cultural values and religious beliefs.	
Competing demands and roles	(j) Competing roles due caregivers' increasing contribution to the labour market, the perceived and actual demands of professional work, employment migration and variable access to/costs of care put a strain on caregivers.	(k) Competing roles may challenge the caregiver cultural self-identity, putting strain on traditional caregiving systems.

Table 2a: Concepts and sub-concepts present in each of the included studies

Study number		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	Presence of the concept across studies [%]
		Globerman, 1996	Yamamoto & Wallhagen, 1997	Sheu, 1997	Browne Sehy, 1998	Sasat, 1998	Harris & Long, 1999	Kao & Stuifbergen, 1999	Chao & Roth, 2000	Kim & Theis, 2000	Van Sjaak Geest, 2002	Jones et al., 2002	Yeo et al., 2002	Jones et al., 2003	Ho et al., 2003	Spitzer et al., 2003	Mok et al., 2003	Leichtentritt et al., 2004	Holroyd, 2005	
Cultural duty and beliefs of obligation		×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	100 %
Gendered cultural expectations		×	×			×	×		×		×		×	×		×		×	×	52 %
Cultural values	Filial piety		×	×		×	×		×	×			×		×		×			57 %
	Familism			×		×		×			×		×	×	×	×	×	×		54 %
	Religious ideas			×		×		×	×		×	×		×	×			×		46 %
Cultural identity		×	×	×			×		×			×			×	×	×		×	57 %
Love and emotional attachments		×	×	×	×		×			×	×	×					×			43 %
Repayment motive			×	×	×	×			×	×	×	×	×	×			×	×	×	63 %
Competing demands			×	×				×		×		×		×		×				23 %

Table 2**b**: Concepts and sub-concepts present in each of the included studies

Study number		19	20	21	22	23	24	25	26	27	28	29	30	31	32	33	34	35	36	37	Presence of the concept across studies [%]
		Wallhagen & Yamamoto-Mitani, 2006	Han et al., 2008	Hinton et al., 2008	Hsueh et al., 2008	Kong et al., 2010	Muoghalu & Jegede, 2010	Parveen et al., 2011	Park, 2012	Qadir et al., 2013	Kietzman et al., 2013	Donovan & Williams, 2015	Meyer et al., 2015	Park, 2015	Ng et al., 2016	van Wezel et al., 2016	Mendez-Luck & Anthony, 2016	Qiu et al., 2018	Zhang & Lee, 2019	Lee et al., 2019	
Cultural duty and beliefs of obligation		×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	×	100 %
Gendered cultural expectations		×			×		×			×	×	×				×	×				52 %
Cultural values	Filial piety	×	×	×	×	×			×			×	×		×			×	×	×	57 %
	Familism		×			×	×	×		×			×			×		×	×	×	54 %
	Religious ideas			×			×	×		×				×	×	×		×			46 %
Cultural identity		×		×	×			×				×		×		×	×	×	×	×	57 %
Love and emotional attachments					×			×				×	×		×		×		×		43 %
Repayment motive		×	×		×					×			×			×	×	×	×	×	63 %
Competing demands			×							×					×						23 %

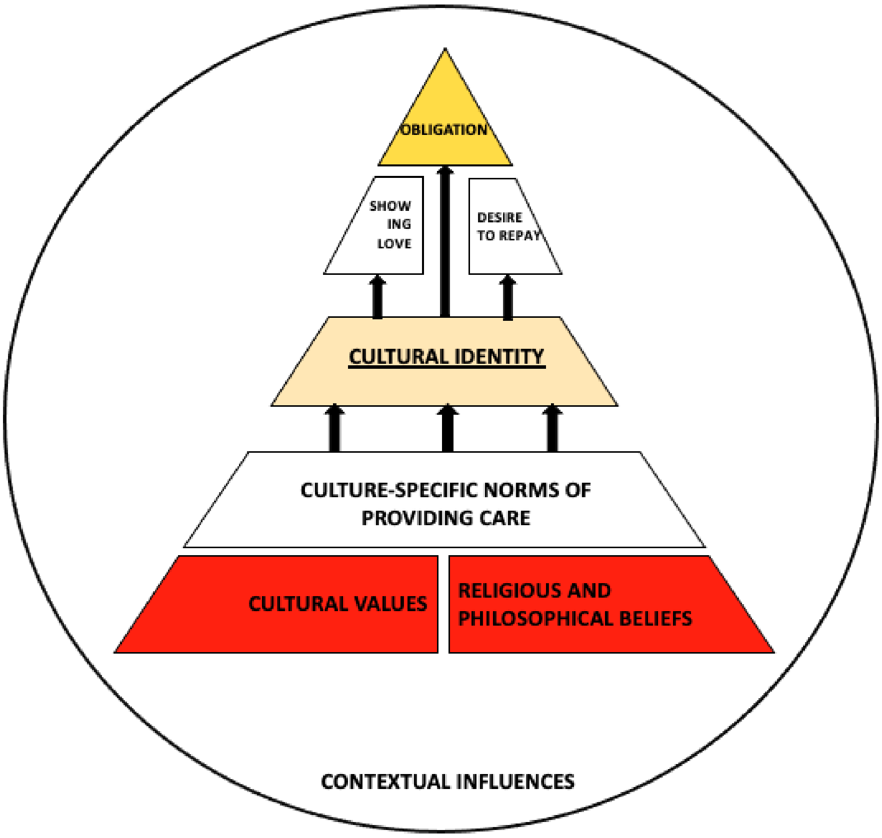

Figure 1 A meta-ethnography pyramid chart with a line of argument

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C1 Appendix - Photovoice prompts

Thank you for taking the time to participate in this study.

Photovoice is your chance to share your ideas about your experience of caregiving, i.e., support provided to your loved one.

Take photos that in your caregiving experiences depict:

(1) why you provide care, your motivation and/or motivators for your caring role,
(2) your values, i.e., things you value the most, things that make your life feel important to you,
(3) any challenges, needs and concerns that you consider relevant to your caregiving,
(4) any gains, assets and strengths that you consider relevant to your caregiving.

You're not sure how to start? No worries!

Here are some tips to help you with these / get you started:

- Take pictures of objects, scenes, possessions, people, services, places that you find relevant and/or significant to your caregiving experiences.
- Remember that it's completely up to you what you consider as your motivation, values, challenges or gains around caregiving. There are no good or bad pictures, ideas, associations or thoughts.
- To illustrate your motivations ask yourself: Why did I become a caregiver, why am I providing care for my loved one? How can you show this in the photos?
- Your values can be seen in different things, whether it is your relationship with someone, your job, your education and training, or your belongings, goods, wealth, values can be seen in more abstract things like love, spirituality or power. Ask yourself: What is really important to me in my caregiving experience? What is a big part of my life? Do I really value this part? How can I show this in the photos?
- To illustrate any challenges, think about any concerns or needs you have that are related to your caregiving. Are there any obstacles in your way? How can you show them in the photos?
- To illustrate any gains, think about the things you are proud of due to your caregiving. How can you show them in the photos?

C2 Appendix – A semi-structured interview schedule

Questions regarding an image choice:

- What is it?
- Why did you choose to discuss this particular photo in this interview? What is the story behind this picture?

Questions regarding the further discussion of elicited issues:

- How do you feel about these issues/things in your life?
- How do they affect you now?
- How do you think they may they affect you in the future?
- How important do you find them to your life?
(in case of the picture representing participant's value(s) the question is: Why does it make your life and existence feel important and significant? In what way?)
- What, if anything, helps you to provide care?
- What, if anything, makes it difficult?
- What, if anything, would you like to change in your situation if you could?

C3 Appendix - Qualitative analysis process

This document describes in more detail the qualitative analytical steps undertaken in this study. The first two stages of Photovoice analysis were applied: *selecting* (choosing photographs) and *contextualizing* (telling stories about the personal meanings of the photographs; Wang & Burris, 1997). IPA was conducted instead of the third, typical Photovoice *codifying* procedure, to process the data content from its 'manifest' level to its' 'latent' level, i.e., from the research interview data (which expresses the participant's experience as lived and reflected upon by the participant) to the 'research phenomenon' (latent meanings and significations) which refers the participant's experience as understood by the researcher in interpretative phenomenological method of analysis (Churchill, 2018; Faucher & Garner, 2015; Graneheim & Lundman, 2004). IPA constitutes a dynamic process between participant and researcher whereby initially, participants attempt to make sense of their experiences, followed by the researcher attempting to make sense of participants' experiences. The researcher therefore engages in a 'double hermeneutic', acknowledging that their own experiences influence analysis during and after data collection (Smith et al., 2009).

IPA is not a prescriptive approach; it provides a set of flexible guidelines for researchers (Smith et al., 2009). Interviews were transcribed verbatim (including pauses, sighs, stutters, tone and laughs). Firstly, the transcripts were read several times and notes of anything of significance and of interest were made. The second stage involved returning to the transcript and using the right-hand margin to transform initial notes and ideas into more specific themes or phrases. This process moved between inductive and deductive positions in that the caregiver's account could generate issues unanticipated by the researcher or the semi-structured interview questions, and the researcher needed to take a theoretically-informed stance to consider how these issues could be conceptualised (i.e., inductively generated codes/themes were contextualised in a theoretically-informed manner in accordance to IPA methodology). At this stage of analysis, caution was essential so that the connection between the participant's own words and the researcher's interpretations was not lost, however during this process existing psychological theory (including health, social, personality, existential and phenomenological psychology) was endorsed, modified, and/or challenged (e.g., by showing that intrinsic and extrinsic motivations may not be mutually exclusive as caregiving out of both love and obligation was evidenced in participants' accounts). Data were further condensed by establishing connections between the preliminary themes and clustering them appropriately. Clusters were given a descriptive label (superordinate- or subtheme-order title) that conveyed the conceptual nature of the themes therein (Smith et al., 2009). The analysis took place first at an individual level (i.e., each transcript analysed individually), and then at a group level, where themes across all transcripts were included. This was an iterative process, with the researcher moving back and forth between the various analytic stages to ensure that the integrity of the caregivers' account was preserved. Tables were produced showing each higher order theme and subthemes. A brief illustrative data extract was presented alongside each theme as suggested by Smith et al. (2009). The process was reviewed by supervisors (VM & DS) providing an audit of quality, validity and transparency (Smith et al. 2009, p. 184).

C4 Appendix – An explanatory memo for the analysis

An example of a coded study transcript in accordance with the initial steps of interpretative phenomenological analysis (Smith et al., 2009) is provided below. *Initial codes* and *emergent themes* in the analysis of an individual transcript are not italicised and are in all colours other than blue in the columns on the right margin of the transcript. *Notes (commentaries)* are in italics and highlighted in blue colour. The exact steps of analysis undertaken are described in more detail in C3 Appendix.

Interview transcript excerpt	**Initial notes & open codes**	**Emergent themes**
Paul: Back so... well how does my family make my life important? I've always had my family as the number one thing in my life. It doesn't matter what else I've got - many [things], property... Well, family first and after that, other things, you know, sorting to line. And I'm a materialistic person? Yes, like nice things like everybody else. But with that, it shows that I'm with my wife after - we've been married for 32 years. We've been together for 36 years. So it's been my whole life basically. You know, I want my daughter... She was... that's her christening [showing a photo], it took me... life perfect. And we, we struggled a lot because the wife couldn't conceive properly. So we tried naturally for many years and it didn't work then. We went to see a doctor. And he recommended that we go to offload, had some tests. And eventually they said 'Yes, you're going to need IVF treatments'. So paid for that. And she's the result of it. And it's funny how that came about because we paid for a fair few treatments. And it didn't work. Because I think it was all a lot of psychologically with a wife - she, she she was always worrying 'We got it? We got it now? And make sure you don't get in, make sure you don't do this other thing you're going to be... tomorrow'. But she was always worrying and then it didn't work and you're wasting thousands of money but it doesn't matter - your money is a tool to enjoy life. So you know if I don't have money, so much, I've still got a life. I got money so they're just gonna make my life better. I'll spend them properly. So after that we went to see.. No, no the doctor has to see us so because he got reports or something from hospital and he said there's money available through this avenue. They will fund you for IVF. Then, because there was excess money, he said, you've got - I think it was like - eight chances, which was a lot.	Value of family Family as 'the number one thing in my life' ***He is presenting a hierarchy of values with family being on the first place; at the same the value of family may be a reason for caring*** Feelings of stability (and security) due to having a family ***He's available for his daughter and wife, but there might be an implicit reciprocity (having familial relations as the basis for the need for safety); the importance of family is highlighted throughout*** Difficulties conceiving children ***Past experiences as a source of meaning attached to having a desired child which is in need of help*** The value of life and family versus materialistic values ***This is another reference to the value of family***	Significance of family Caregiver's own (unique) story Significance of family

So started off. One month. And we missed another month, and another month. It went all the way on, nothing happening, because they've got to do the test. So long, long period. Now it passed. And eventually, you know, the last month came along. And the wife was downhearted as you can imagine, and, you know, she she just said 'Oh, last time'. And, you know, she'd always been dropping hints about adoption and stuff like that. So I don't mind because I'm adopted. And so I don't mind at all, look at me as a child, but, you know, I think I'd have more.... Much more feeling if it was my own. She just went 'Okay, let's go for the last one'. The last one worked. The very last time actually worked and Julia was the result of it. So, I don't know... it was just a very, very good feeling that from all the worry and the stress and everything, that's once the wife relaxed. And, you know, that's, that's the important thing in life for me and since her birth, you know, we've just cherished her, looked after her. And the bond, that's actually grown, is very, very tight between the family. And it's funny, you know, her mother, she's just absolutely everything for her, absolutely everything. And it's not that I don't do nothing but I'm into the background and I get the most respect. Yeah. The bond that we have as a father and daughter is endless all times and even this week because I have to to spend so much time in bed now with my leg elevated, she bought me a fire stick. So I could watch telly or some nice films and not going downstairs. Then she bought it and said 'It's for you, a present for you'. You know, something that I told her 'Listen, don't tell your mom. When your mom comes in, just tell her that you bought a fire stick for us. Not for me'. Not so she did. So, you know, I keep telling her that, you know, she is... She'll give me a bottle of wine. She gave me this year. But what I do for that is, in some ways very materialistic. Like, you know, she's got her own three bedroom house now. And because I'm able to do most things, I went there, did all the decorating, put new wooden floors in the house, put all the curtains and the blinds up, completed the back for the new stach, did the garden. You know, everything. Of course, as a 'thank you' from her and her fiancé, they bought me a couple of bottles of wine. And... I'm tempted to use but that was my wife's, you know... but she doesn't realise that when we're not doing stuff and that's the difference, I	Difficulties conceiving children *Experienced by him – stressed by the mental state of his wife* Difficulties conceiving children Difficulties dealing with a partner's stress regarding above difficulties ***Experienced by him – stressed by the mental state of his wife*** A desire to have offspring ***Past experience (problems conceiving when they really wanted a child) - current caregiving (a daughter that was ever wanted, and expected, and investments made)*** Cherishing the child Tight bonds (in the family) ***Tight bond with the CR, a good rapport-relationship quality*** Good relationship/rapport (between the carer and a care recipient) Care recipient's gratitude ***CR's gratitude, signs of appreciation may also be part of reciprocity; or is it more symbolic?*** Care recipient's gratitude Deriving satisfaction from helping (caregiving) ***He's comparing his caregiving to his wife's almost as though he and his wife were 'fighting' who's caring more for their daughter*** Care recipient's gratitude ***Signs of generalised reciprocity? What would be the difference between reciprocity and gratitude as expressed by his daughter?***	Caregiver's own (unique) story - Difficulties conceiving children Caregiver's own (unique) story - A desire to have offspring (investment) Caring relationship (Relationship quality) Caring relationship (Care recipient's gratitude) Caring relationship (Care recipient's gratitude)

think. When I do a lot of stuff - even though I gave a lot of emotional help to them - you can see what I do for her and I think that triggers something in Julia's mind. When she's out somewhere with friends or she's in above, you know, 'My dad did this, my dad...' So even though her mother does lot more - because you know her mother takes the little boy to swimming, she used to take him to karate, she's involved in it - but the bigger things were, you know, where my wife gives emotional and just support that nature. We've got a quad for the boy [Julia's son] and even though my my wife 'Let's go out...'. Okay, just give me the tyke and we're going together and put the court in, check it out and off he goes in the fields in Caernarfon. So what this little man remembers is tight... Me. You know, there are time when they are very, very, very cautious with it, don't speed up, don't go too fast, always do this, always do that and instead, you know, sitting on this quad after that... I've got, you know, because I'm the only one, he just looks up. Hey, as fast as you go, off you go! And then she's panicking. Listen, if he comes off, you...	Being praised by the care recipient Care recipient's gratitude ***Feeling appreciated by the caregiver as a motivator to continue caring*** Spending time with family Taking care of care recipient's child ***The significance of moments spent together with a family as an exemplification of the value of family***	Significance of family

C5 Appendix – Qualitative findings with overinclusive list of supporting caregiver quotes: A long draft version

Within this section, a brief description of the typical photographs caregivers chose to discuss during their interviews is provided and followed by the results from IPA analysis of caregiving interviews.

Six superordinate themes were identified. The themes are:

1. Caregiver's life story
2. Significance of family
3. Caregiving obligations and responsibility
4. Caring relationship
5. Perceived and actual challenges and caregiving motivations
6. Perceived and actual gains and caregiving motivations

The superordinate themes and their subthemes (in bold) are presented, with illustrative quotes included.

Photograph choice

Some photographs contained care recipients to represent reasons for caregiving such as affectionate feelings, relationship quality, family values or to signify care recipient's deterioration, stabilising or improvement. Some caregivers chose photographs of themselves or taken altogether with the care recipient to symbolise their obligations/responsibility to provide care or care recipient's gratitude. For example, a photo depicting caregiver and care recipient's hands holding with visible wedding ring represented caregiver's sense of marital obligation as a motive for caring. Caregivers often chose photographs of objects, which had various meanings attached. Some symbolised the significance of family and/or obligations, e.g., photos of home symbolising the importance of family bonds. Some photos of objects symbolised the strains or challenges they were experiencing at the time of the interview and their inability to escape from caregiving. Photographs of objects depicted also gains from caregiving. For instance, a photograph of baby clothes hung in the garden signified the strength of familial bonds and meaning derived from caring for the care recipient. Photographs of objects showing caregivers' ability to escape from caregiving, such as pets, gardens or books, were also often popular choices.

Superordinate Theme: Caregiver’s life story

This theme encompasses: key features of caregivers’ autobiographies; personal characteristics; situational circumstances; and changing trajectories in the care recipient’s own health condition over time; all of which related to undertaking of the caring role and its continuation.

Subtheme 1: Past experiences

Caregivers reflected on their past life experience when considering their motivations for caregiving (initial or continued), connecting the selected past experiences with their current caregiving.

Alice, Emma and Paul, caregivers for their adult child, described their earlier in life desire to have children and what being a parent meant to them. Many years prior to their adult child’s brain injury, they had been strongly focused on family, considering having children a precious experience. These experiences provided a source of meaning and the investment in children contributed to both the motivation and willingness to take on the caregiving role and to continue with it.

> 'Cause I lost one [child] before and I lost two after her. Yes, I wasn't supposed to have any children. So, it took seven years for Joan and five years for Sarah. So, I'm lucky I got them. (Alice)

In addition, having previously been a caregiver for a different family member, was another important factor that, for some, related to their current caregiving situation. Alice, Siân, Ceri and Florence drew links between these past experiences and their current situation.

> So that's another thing. So, I was the only one that used to deal with him [her dad suffering from Alzheimer’s disease] before we had to put him in the [care] home because my sister, my brother, they couldn't face it. So, I think that's where the caregiving comes from. So, it's just automatic. […] So, I think that's just, just the way, that's just my care. (Siân)

Subtheme 2: Personal characteristics

The personal characteristics mentioned by caregivers included their caring nature, patience, dispositional optimism, and independent nature. These characteristics helped sustain continued motivation for caring. For instance, Alice related to a predisposing characteristic of being caring.

> I’m too soft and I care too much for them, but I don't know if you can get too much for anybody? (Alice)

Subtheme 3: Situational circumstances

This subtheme focuses on the importance of situational contextual factors that made caregiving possible in the first place for the caregivers and facilitated the continuation of the caregiving role, including: having the ability to retire and being eligible for state pension, having financial resources, and the caregiver's own health status.

All caregivers except for Emma were around retirement age and eligible for state pension, and having the possibility of retiring and accessing their pension were often a factor in undertaking the caring role.

> So yeah, luckily, I mean, I was just about retirement age. I had planned on working a couple of years longer, but it didn't matter. (Ceri)
>
> We have pensions and things like that. So, we're not that restricted. […] but because I was so close, I was able to access my works pension. So, it wasn't a case of woman as working and next minute I had nothing else nothing, no money coming in. (Siân)

Alice, Emma and Siân had their own health problems which impacted on their ability to carry out practical or physical caregiving responsibilities (e.g., such as lifting someone from the bed). It did not seem, however, to decrease their motivations and willingness to provide care, i.e., they were highly determined to provide care. Apart from personal or practical care, caring entailed social and emotional care, as well.

> The diabetes has always been brutal. It's never been easy. But suppose you shove it to the back of your mind. This [caregiving] is more important than... you know. Joan's more important than the diabetes. (Alice)

Subtheme 4: Changing trajectories in the care recipient's health condition

Findings consistently illustrated that caring was a complex and dynamic experience, shaped by a myriad of factors including changes in the care recipients' health and their associated care and support needs. Caregivers referred retrospectively to the changes in caregiving tasks and responsibilities that they had experienced due to changes in the recipient's health condition, but they also projected the future course of caregiving based on possibilities/expectancies of the recovery as well as stabilising and decline, as illustrated below.

Unsurprisingly, there was less motivation to continue caring amongst those caregivers who had less optimism about the care recipient's recovery (Luke, Dylan, John), compared to those who perceived higher chances for the recipient's recovery (Joan, Tom, Julia, Harry).

> It's changed, you know, something that was really bad that's got better over time. And so it just depends with what stage. It went from, I would say, almost paralysing to now, mostly absolutely fine. […] The overriding thing is just wanting things to carry on getting better or at least just stay the same. (Emma)

Similarly, Emma also reflected on her caregiving journey – from the more difficult beginnings to the point where Tom's positive progress left hope for the future, with joy seen in her words about getting back Tom's identity. The positive changes in Tom's condition maintained her continued caregiving motivation. Ceri also thought that Harry had made very good progress which was a source of hope for an improvement in their lives, shaping also her motivation to continue in her caregiving role.

> The time of stroke was pretty grim because it was quite bad stroke… But yeah, he's made improvements over the time. I think you do reach, they always said, 'Oh, he'll reach a plateau and you won't get any better'. But you always live in hope, you always think 'No! What do they know? *We will show them such a thing'*. And I think he has... (Ceri)

In contrast, Sian's, Florence and Will's perceptions of deterioration in the care recipients' condition, or a limited recovery, contributed to the expression of doubts about the future and reduced hope for improvement. The adverse impact of the care recipient's negative progress on caregiving motivations was hinted at (e.g., with caregivers expressing disappointment or an overwhelming burden, both impeding caregiving continued motivations).

> Yes, that's the way I feel. So now, I don't know how long that will, you know, how long it will last because he... What can I say? The damage really that the stroke has done to him. It's something's he's never ever going to get over completely. And of course, I'm always on... back your mind, I mean, we've been married for 45 years, like so. We've been together for all that time. And then I first thought towards the end when I was getting, you know... doing a lot more things independently. (Siân)

Superordinate Theme: Significance of family

This theme captures the importance of family, familial relationships and family roles in determining caregiving motivations.

Subtheme 1: Family values

Family was highly valued by caregivers and they strongly identified themselves with an idea of family.

> Well, family first and after that, other things, you know, sorting into line. (Paul)

Family values were exemplified as spending quality time together, maintaining a sense of ‘home’ (i.e., keeping family close by, emotionally and physically), and familial solidarity (as reported in five relationships out of eight in this sample). Family values underpinned a sense of responsibility for family members (see theme ‘Caregiving obligations and responsibility’) and as such influenced both initial and continued motivations for caregiving.

> My main job is looking after the family. And my family bubble is, you know, my grandson, my wife, Julia, that's it. And my purpose in life is them. You know, I need to keep them happy. So, I look forward to... what are we going to do? When are we going to do it? (Paul)

Alice and Emma indicated a difference in family positioning whereby the nuclear family was prioritised over the extended family. Additionally, the relationship type within the nuclear family had importance for these two mothers where children’s care needs were prioritised over their partner’s needs.

> Yeah, they were the most important - if it was a choice between... What I've always said that [if] it was a choice between a husband and my children, I would choose my children first. (Alice)

Josephine’s account strongly emphasised the relationship between the family and herself, the familial self. When she referred to the family as the one that ‘made her’ or as ‘part of her’, she projected a strong image of herself as a family member, highlighting her roles as a mother, wife, daughter as well as the significance of her familial self-identity and its embeddedness in herself and in her actions (and motivations). Familial self was the medium through which the family values were displayed and underpinned some caregivers’ motivations, implying importance to possibly both start the caregiving role and continue providing care.

> I think they're all important because I think they make... they made the people that we are, aren't they? You know, they're important to me. Not because I look after them because they look after themselves mostly... It's not why. [pause] Because they're family, aren't they? They're important because they are our family. (Josephine)

The sense of familial responsibility was evident in caregivers’ narratives and concerned explicit obligations and responsibilities (see theme ‘Caregiving obligation and responsibility’) that were rooted in family values. Josephine, Ceri, Florence and Will described caregiving as a familial responsibility. Being a relative of a person with a complex health condition, they felt obliged to provide care with the value of family underlying the obligation and a sense of responsibility to care, both initially and over time.

> We feel that all family *should* look after each other. (Florence)
>
> So yeah, we took him [started providing care] because we are family. (Will)

Subtheme 2: Kin-keeper

The term 'kin-keeper' refers to the caregiver's perceived responsibility for keeping family members connected, for the continuity and integrity of family relationships and of the caring relationship. For example, through facilitating communication and interaction between family members, Emma, Josephine and Siân were acting as kin-keepers - taking responsibility for the effective continuity of family relationships, including with the care recipient. Assuming the role seemed to have its roots in their life histories (see theme 'Caregiver's life story') with caregivers associating their 'kin-keeping' characteristics with an anticipation to provide care.

> So, everything was always left to me. So, I thought... my father always used to turn to me for that, you know. Different things like you know, it always was me that he always turned to. That's just, that's just a general background just for me to think why I'm the person I am, where the caregiving comes from. (Siân)

Often, the role of the kin-keeper came at an emotional cost in the context of brain injury caregiving, for example, Emma felt that as a 'mum of the family' she had to hide her feelings and felt responsible for 'making things okay' in her family, maintaining the integrity of the family (ill son, annoyed husband, three other younger children to be taken care of). Inevitably, this left her with the perception of carrying most of the caregiving burden. The motivation to sustain a sense of normality and family functioning, in otherwise unfavourable circumstances, was highlighted.

> I think my husband felt frustrated with everything that was going on [Tom's brain injury] and because I was trying to make it okay, I think he thought I was in cloud cuckoo land believing it. I was just trying to make things okay, you know, for the children, for the rest of the family. (Emma)

Subtheme 3: Familial support

Perceived and received familial support motivated caregivers to continue to provide care with family networks supporting the caregivers emotionally, socially and practically and helped uphold the investments in caregiving.

> Because although we've got a fantastic family. They might come a day when I might need help, ask them for help. They will be there like a shot. So yeah, they're pretty important. (Ceri)

Florence and Will expressed ambivalence about obtained familial support; whilst they appreciated the emotional support they received, they felt that other family members could not entirely understand their caregiving situation (e.g., by suggesting, as seen below, that informal caregiving is an ‘easy job’). This ambivalence motivated them to continue providing care themselves, as they did not believe that other family members could provide personalised support to John.

> ...and they all [other family members] said, ‘Hey, you’ve got an easy, cushy job!’ It’s because they haven’t seen John to his full [worst] potential… (Florence)
>
> We can discuss things [with the family] but they won’t… with the nature of John, it’s no good them looking after him. (Florence)

Superordinate Theme: Caregiving obligations and responsibility

This theme describes the norms and expectations underlying motivations to care and to continue caring.

Subtheme 1: Parental obligation

Parental obligation to provide care to an ill child was related to the social norm of being responsible for ‘the life you bore’ with caregiving seen as an extension of the parental obligation to support a child.

> Of course, you look after your children, don't you? No matter how old they are. They're always your children till the day you die. So why would you expect somebody else to look after them? (Alice)

Caregiving typically entails changes in roles whereby adult children with brain injury in need of care and support become more dependent on their parents and parents take on caring responsibilities above and beyond what is expected of such relationship. Parents in this study expressed more willingness to provide care for their child rather than for other family members, a hypothetical reflection rather than reflective of actual decisions that had been taken. Emma realised that ‘you easily slip into the caregiving role’ as that was the norm of being a mother. Similarly, Josephine also highlighted that caring for a child is something she has ‘never stopped doing' as that is what being a mother meant to her, only the boundaries of what it entails changed following acquired brain injury.

> If I had to be honest, much as I love my husband, I wouldn't look after him so willingly. […] I think it's a different relationship. With children you want them to grow up, you want them to be adults, you don't want to look after them when they're big, certainly. But if you have to, you do and that's your role. Yeah, I think you easily slip into that role because you're their mum, and I wouldn't happily step into that role for my husband because I don't want to look after him. (Emma)

Subtheme 2: Marital obligation

Spousal caregiving comprised the fulfilment of marital vows and perceived norms of being a spouse ('a natural part of marriage').

> I'm not his carer, I'm his wife, you know, in a marriage, it's mutual love and respect. So, this label of carer, I struggle with it, I don't see myself as a carer. I'm just his wife, and we go on with it. (Ceri)

Although Siân acknowledged spousal obligation as one of the motives for initially providing care, she felt that it was not a sufficient motivator to continue caring. Her desire to relinquish the caregiving responsibility was contradictory to her perceived spousal obligation and affectionate feelings toward her husband.

> I think it is a natural part of marriage - caregiving. In marriage even if there's nobody, you know, nobody's had a stroke or whatever. It's just that when [something happens] you just automatically step up. So that's part of it - yes. Caregiving. Definitely. (Siân)

> I find it sometimes... it's frustrating because I'm, I think to myself: by now he should... he should have developed his own routines for doing things but he still hasn't, but *I'm done with it*. I feel sometimes a bit selfish. […] Yeah, well because he, because obviously he had been ill like and here am I thinking to myself: I must be selfish person if I can't think about. (Siân)

Subtheme 3: Caring responsibility

Perhaps *responsibility* should be distinguished from the *obligation* as in many instances caregivers referred to 'family responsibility' as related to obligation (i.e., general norms and expectations that make them undertake the caregiving 'responsibility'). However, responsibility - on the grounds of social and existential psychology – can still imply the presence of choice. For example, in case of caregiving a choice may refer to relinquishing caregiving into other family members or formal services as well as a choice to accept it and provide care. Personal responsibility seemed a foreground for Will's sense of agency, his caregiving motivation. The inferred difference between responsibility and obligation was derived from the discussion on the perception of caregiving obligation that was viewed differently by the caregiving couple, Florence and Will, who had a discussion of the choice in providing care to Florence's brother. Both of them reported that caregiving was motivated by a sense of familial obligation/responsibility, however, Will disagreed with Florence's view that familial obligation entailed a lack of choice. Even though obligation may imply no choice, the individual's perception of obligation may not support this assumption. The paradox of choice was exemplified by the differing perspectives of making one's own decision (by Will) and a lack of choice (as perceived by Florence). In line with existential thoughts (e.g., Frankl, 2011; Van Deurzen, 2009), having a choice is always present and is a central attribute of a person. There is in fact only one choice that people do not have and that is not to choose – and not choosing in itself represents a choice (e.g., Sartre, 1948). It may be hard to challenge the existing norms, obligations, expectations and circumstances (e.g., societal and cultural ones around family-based caregiving), suggesting a perceived lack of choice (see for example the literature on the perceived choice or lack thereof in providing informal care; Pertl, 2019). However, Will's perception of having a choice in providing care viewed against his wife's perception of having no choice in caregiving comprised a powerful example of attributing caregiving motivation to *personal* responsibility, i.e., responsibility that is not guided by general caregiving expectations or norms (e.g., that family should provide informal care), but by one's *own decision*, whether that is to provide care, or not.

> We didn't have a choice… […] it was left down to... [us], we had no choice but to do it. It was basically forced upon us. (Florence)
>
> No, I think it was a choice. There was a choice. […] We had everything in place that we could do it so we said, 'well, if we can do it, why are we not doing it?' So, we just did it anyway. I suppose it is an obligation, because he's family. I mean if he wasn't family, I don't think we'd have done it for anybody else. […] But there was a choice. (Will)

Superordinate Theme: Caring relationship

This theme focuses on the nature and quality of the relationship between the caregiver and the care recipient.

Subtheme 1: Affectionate feelings

The emotions of love and affection toward the care recipient were amongst the most often reported motivations for initial and continued care provision, with cognitive aspects of emotion also evident, as described below.

Emma, Josephine and Siân spoke about their love towards the care recipient relating to affective, embodied and intuitive properties of this emotion. Love was described as a primordial and natural force, making them act ‘without thinking’ or ‘questioning’, i.e., non-cognitively. Affection could be seen as an embodied emotion that drove the caregiving and which existed before the caregiving commenced (‘I love’ and ‘I care’ as entwined in caregiving action).

> I think you would call it - if you love somebody, you will automatically give them care. You know, you look after them. Give them the care, caregiving. (Siân)

Affection was also experienced as a cognition (belief) amongst most of the caregivers, e.g., that love *should* be part of familial relationships (love as an expectation). Love as a cognition seemed a more logically thought-through decision or part of existing role expectations (and thus responsibilities) as compared to a natural, automatic, emotionally-based experience of love. Ceri shared examples of behaviour which depicted her love toward Harry.

> But yes, it's mutual love and respect. It's being together. It's sharing things. It's sharing your problems, listening to him. He listens to me. Discussing everything. It's just your life together. (Ceri)

Often, it was noticeable in the caregivers’ language that an affective state such as love brought with it responsibility and obligation which elicited both positive and negative effects. Given that the caregivers’ accounts were replete with diverse caring motivations, it is perhaps not surprising that caregivers described love and obligation simultaneously. Siân pointed to both the obligation arising from the marital role and affection.

> Because he's my husband. [laughing] I still love him. Yeah, 'cause he's my husband I care about him because I want his life to be happy. So, I try to do as much as I can to make his life happy. (Siân)

Subtheme 2: Relationship quality

Relationship quality, including the perceived quality of current interactions and the strength of the bond between the caregiver and the care recipient (past and current), was another factor influencing initial and continued motivations to provide care.

Existing relationships were either described positively, i.e., pertaining to close emotional and familial relations and their appreciation, or negatively, i.e., relating to distant or strained relations[4]. The former was evidently more prevalent (in Paul's and Ceri's accounts) with the latter also evident in three accounts (Siân's, Florence and Will's).

> Another motivator I've got with her is - since she was a very young child... maybe from one year old onwards, we would always take her out. We would never go out without her. We never asked anybody to babysit. […] The bond that we have as a father and daughter is endless all times and even this week because I have to spend so much time in bed now with my leg elevated, she bought me a fire stick. (Paul)
>
> He doesn't realise how much William and I have given up and we've tried to tell him, and it just goes in one ear and out the other, he just shoves it off and yes, there are times when the tension is high here and we just want to throttle him, because he doesn't care and that's what hurts the most. (Florence)

Subtheme 3: Care recipient's gratitude

The concept of gratitude is closely related to reciprocity i.e., the reciprocation (repayment) of the past 'debt', however it is conceptualised as something more voluntary, intentional, and focused on symbolic appreciation for help given rather than reciprocation (repayment) by returning help. Caregivers' perception of the care recipients' gratitude for their caregiving appeared consistently as motivation to continue caring (after having been in the role for some time).

> The best reward that I get out of that challenge for me, is her face and her thankfulness for doing it. Because you know she'll, she'll come and give me a kiss or a hug which is worth a million pounds for me. (Paul)

Superordinate Theme: Challenges (perceived and actual) and caregiving motivations

This theme focuses on the link between caregiver motivations and perceived and actual caregiving challenges.

Subtheme 1: Negotiating roles

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[4] As highlighted before, caregivers' accounts were replete with diverse caring motivations, and distanced/strained relationships did not exclude the motive of love, i.e., two caregivers (Florence, Siân) mentioned both the negative relationship quality and love for the care recipient.

Care and support needs arising from a sudden and traumatic onset of stroke/brain injury were the cue for the caregivers to assume their role (initial motivation). This required caregivers to take on different and varying degrees of responsibility over aspects of the care recipients' lives and, at times, temporarily making decisions on their behalf (when assuming and later in their caring role).

> He [John] was going to the library to do maths – 2nd chance Maths and 2nd chance English, and we would sit here and try and help him with his reading, and it's almost like looking after a 5-year-old child, yeah, but he's in a grown-up body so... (Will)

Some caregivers felt that they had to assume some of the care recipients' responsibilities, either because the care recipient's disability prevented them from doing certain things themselves or because the care recipient might have relinquished certain tasks and assumed the 'sick role' (Parsons, 1975). Paul distinguished between the two, showing, with regards to the latter, that Julia sometimes expected him to do things for her, i.e., a learnt dependency that he resented. Nonetheless, these challenges (i.e., assuming some responsibilities due to care recipient's disability and/or the 'sick role') were motives behind the provision of care, i.e., either impacting the caregiver decision to provide care (initial motivation) or being present afterwards (continued motivation).

> She understands her limitations. So, she always brings everything to me, and then I will look at it and that I will make the decisions. (Paul)
>
> I know she has a brain injury. And I do know that she's forgetful. But on all occasions, you know, she's... lazy with it. (Paul)

It was not easy for caregivers to establish boundaries in the caregiving roles. They were not certain how to re-negotiate the boundaries in a relationship and expressed doubts whether they were doing 'it' correctly. This renegotiation underpinned caregiving motives, for example Siân recognised that by increasing Dylan's independence she could prepare him, hypothetically, for a situation in which she could no longer be needed to provide care.

> Probably that he will take a bit more control over certain things. I mean, I've tried to push him, push him regarding monetary things like paying, paying the bills. He has his own, he has a credit card. […] But it's just... he.... just to get him a bit more independence as well because, I mean, I'm not gonna always be there for him. You know, for some reason, you can never tell. So, he needs to start moving away from being totally dependent on me. (Siân)

Increasing the care recipient's independence was experienced as a motivating factor by some caregivers, for example, Josephine, who was providing care with her main goal being her care recipient, Luke, re-gaining as much independence as possible:

> So, it just gets his... to get his brain working on something else. I don't know if it works or not, but just you know, just to get on moving or doing something different.... That's the motivation for me doing the things that I do because hopefully he will do it himself or some of it. (Josephine)

Subtheme 2: Feelings about support from services

All caregivers, except for Emma (who did not mention support services at all), expressed dissatisfaction with support from services.

The feeling of abandonment appeared to be a strong indicator of caregivers' dissatisfaction with services. Discharging a care recipient from hospital prompted the caregivers to 'step in' and take over the caregiving role that a lot of them felt ill-prepared for, leaving them with a sense of being left to their own devices. Caregivers' ability and willingness to provide care for the care recipient seemed to be taken for granted by professionals involved in assessment and support planning at the point of hospital discharge and services. Therefore, limited service response left carers feeling they had little choice but to care.

> They all just left us. Well, what do we do now? You know, how do we manage? Nobody gave us any advice as to how to go forward with John or do anything like that. They just said, 'Well, that's not up to me, that's somebody else', and well, 'but, who do I talk to?' (Florence)

Lack of personalised and responsive support from statutory services fuelled frustration. Several participants revealed strong resentment of service providers (Alice, Josephine, Florence and Will) although this perceived lack of support actually enhanced their sense of obligation (their caregiving motivation) as they felt the care recipients were predominantly reliant on them.

> Yes, I'm not able to do something. [talking through tears] I think it's annoying because that's the thing, not just Luke, but lots of people need help but it's not there. There's nobody. It is that when he first had the injury, then there is a lot of help there... Different... different doctors, I can't even remember now. (Josephine)

Three participants (Alice, Florence and Will) had negative experience with social workers, feeling that they were not understood by them and that they caused more harm in their situation (e.g., suggesting establishing 'the routines for each day of the week' which were annoying for both the caregiver and a brain injury survivor).

> They were bloody useless. It was like talking to a brick wall with some of them who were social workers. They weren't interested, interested at all. (Alice)

Florence and Will felt that healthcare and social care practitioners were supportive to the care recipients, but that the caregivers' story/voice was not heard. They felt unsupported/unacknowledged by them and this feeling might have contributed to the perception of the lack of choice in providing care that Florence expressed, effectively narrowing down other potential caregiving options/arrangements (see subtheme 'Caring responsibility'). Tacitly, in her case this seemed to sustain her caregiving motivation to provide care to John (rather than demotivate her).

> When they build up, they become big problems. And if you go and try to discuss that with Gary, he seems to side with a person with a brain injury rather than listen to what the carer has to say. And so, we stopped we didn't really want to go after that. So far, I didn't. So, we stopped really going. (Florence)

Subtheme 3: Coping with caregiving challenges

The range of coping strategies indicated by carers reflected the dynamic and contextual nature of appraisals, coping and the use of coping resources such as support systems. Caregivers' accounts pertaining to coping strategies are each represented by *cognitive-emotional, emotional-social* and *action-oriented coping,* with evidence that these related to continuation motives.

Cognitive-emotional coping refers to strategies which involved: persevering in the face of challenge and gaining a sense of control over the caregiving situation, developing expertise, acceptance of the caregiving situation. Successful coping efforts (adaptation) supported caregiver motivations.

Persevering in the face of challenge was described by Florence and Will. By focusing on the present moment, they felt they were gaining more control and understanding of the impact of caregiving on their lives. Focusing on the present moment helped maintain motivations to provide care.

> So that, yeah, we had a major challenge. We do get through it. And it does take its toll, but we move on. And we wait and take each day at a time. That's the only way we can live, by taking one day at a time. (Florence)

With time, the changes in both caregivers' and care recipients' lives were accommodated and some of them knew better how to deal with them., i.e., either the care recipient's condition improved and/or caregivers felt better able to cope having gained knowledge and experience of the health condition and ways of dealing it with. An emerging sense of self-efficacy in the caring role (i.e. a caregiver belief that they can successfully meet the challenges of caring) motivated continued caring.

> Yeah, I'm getting used to... I probably got used to it now over the last 12 months. So, it doesn't, doesn't get me frustrated, doesn't get me annoyed as it used to. (Siân)

Acceptance of the caregiving situation presenting limitations on daily life and in relationship with John featured in Florence’s words. Similarly, it helped sustain caregiving motivations.

> We take life… we take each challenge as it comes, that’s what we do. (Florence)

Emotional-social coping referred to the use of support groups and family support networks (for the latter see theme ‘Significance of family’). Support groups were a particularly valuable source of support for Siân where talking to other caregivers and observing other people experiencing the consequences of stroke/brain injury helped her normalise her own caregiver experience. Accessing social support from peers (as needed) helped her continue with caregiving, shaping her belief in an ability to cope.

> It [support group] makes me feel less guilty. The way I feel because then I'm thinking, well, it's not just me that feels this way. Other people feel the same. So, it must be something general. When you’re a carer for somebody, yes, you worry about them, you want to do the best for them, but because we're all a bit selfish now so we still have to look after ourselves. It does help because among people, I'm not the only one, this is normal, this must be normal. (Siân)

Action-related coping referred to actively searching and gathering information about the care recipient’s health condition to achieve understanding of what they were experiencing or might face in the future. Alice engaged in active coping by gathering information on Joan’s brain injury to understand it in a better way and to know how to cope with it, thus helping herself sustain motivation to provide care.

> Because I went to the Internet when Joan was diagnosed. I wanted to know everything about it. What's that thing, what the prognosis was. How it's diagnosed, how she got it. Because I've had Sarah checked. Because there's two forms, isn't there? It was like a hereditary one. I couldn't understand... Couldn't understand how Joan got it. Seems it's just bad luck really. (Alice)

In addition, utilising short breaks from caregiving helped to manage caregiver strain and to sustain a life alongside caring, all of which were helpful in sustaining continued willingness to provide care. Ceri, Siân and Paul managed to take personalised short breaks from caregiving. These breaks had a positive impact on their wellbeing, helped them attend to their own needs and re-energise, facilitating their willingness to continue caring.

> I mean, if I want to get out of the house, just myself, then I can at least say: Right, I'm going to go into town or something like that just to go, get somewhere or something

> like that. That just gives me a small break away from him. So, I've half an hour or something like that, but it's just that breakaway. (Siân)

Superordinate Theme: Gains (perceived and actual) and caregiving motivations

This theme reflects on the caregivers' rich descriptions of the positive aspects of caregiving as associated with caregiving motives.

Subtheme 1: Gaining new experience and skills

The general experience of caregiving was interpreted in terms of a learning process in which challenges were either overcome or managed, thus leading to subjective feelings of gain, which in turn supported motivations to continue to care. For example, Josephine highlighted that 'helping the care recipient' was generalized into an attitude of helping others which she felt was a gain: in seeking help for Luke, in the very activity of doing it and accompanying him, she realised the experience was an opportunity for reflection and for making new social contacts- for her, the experience of caregiving gains was a strong motivator to continue caregiving.

> I think it's a definite gain and another gain is also that me and Luke met different people at [name of the charity organisation], different people at appointments. He's been to different brain injury units to help other people that are suffering. So that's all a gain. For all of us really. And that's also a part of being caregiver, what I keep doing and wanna do. (Josephine)

Subtheme 2: Reflections on life: post-traumatic growth and resilience

Caregiver's wellbeing was challenged by their caregiving experiences (see theme 'Challenges and caregiving motivations'), nonetheless, for some, the difficult moments turned out to be an opportunity for reflection underpinning a sense of happiness, relief at having coped or a sense of achievement. This was a form of happiness highlighting the eudemonic, rather than the hedonistic nature of wellbeing. Caregivers were often surprised to discover that the experienced trauma or burden (reported elsewhere) constituted an adversity that enabled them to become stronger and to grow, i.e., led to edification, personal growth and resilience. For instance, Paul reflected on the trauma, anxiety and depression that he experienced as a result of the challenges presented by caregiving following his daughter's brain injury (reported elsewhere); for him being engulfed in caregiving became a way to grow as a person and find new ways to appreciate life. He often mentioned that he chose to be a caregiver, i.e., that he knew immediately following the brain injury that he wanted to care for his daughter. Exercising a free choice to become a caregiver was key to his post-traumatic growth, being able to stand on one's feet and perceiving caregiving as rewarding impacted positively on his motivation to continue caring i.e., he derived satisfaction and meaning from providing care.

> …motivation to help is a motivator to keep on helping. Because I enjoy it and now, like with solitude, solitude... [I] feel free to plan the life I want for us as a family. (Paul)

Interestingly, caregivers who did not feel they had a free choice to become a caregiver (see subtheme 'Caring responsibility'), such as for example Florence, perceived less gains from caregiving overall and none with regards to post-traumatic growth/resilience, as compared to those who felt they exercised free choice to assume the caregiving role, as exemplified by Paul's case. The motivations of the former group seemed to be centred more around family values (see theme 'Significance of family'), obligations to provide care (see theme 'Caregiving obligations and responsibility') and overcoming perceived challenges (see theme 'Challenges and caregiving motivations') than for the latter group.

Subtheme 3: Patience, understanding and empathy

Caregiving experiences shaped carers' personalities and, bidirectionally, their personalities influenced their experience in caregiving, including motivations. The most often cited developments or changes in traits (that were manifest as behaviours) included more patience, higher compassion and empathy toward others; all of which comprised a tacit motivator to provide care. Other qualities were being calmer, developing more tolerance (i.e., developing willingness to tolerate the existence of behaviours they disliked or disagreed with), developing different life priorities, being less selfish, learning what stroke and brain injury survivors think and need, and being more organised. This was reflected in the importance of the social values (i.e., altruism, love of people) reported by the caregivers, i.e., their recognition of these values as part of their self-growth as individuals.

> So, the strengths, definitely, patience and empathy. (Emma)
>
> Yeah, you more understand it, and you've got more of an understanding… (Florence)

Paul found meaning in helping his daughter and as described above his self-growth translated into the experience of the caregiving gain – which he embraced as his 'main motivator' to continue caring for Julia. Motivation to provide care derived from the self-growth and a meaningful purpose in life.

> So that is my main motivator, that I can find purpose in helping her - and that motivates me that I've done a good job. And if everybody's happy in the house as I said. (Paul)

Appendix C6 - Information Sheet

Research Study Title:

An exploration of values, motivation, and perceived challenges and gains amongst informal caregivers

Invitation:

We are conducting this research study in order to identify and discuss the factors that are important to Caregivers' experience - their values and motivations, their experience of gains and challenges.

You have been invited to take part in this study because you are currently providing care to a loved one who is experiencing illness or disability. By reading this information sheet which describes what the study involves, we hope you can make an informed decision about whether to take part or not.

If you would like to take part in the study, please complete the attached 1) consent form, 2) questionnaire and 3) Photovoice consent forms as applicable, and return them to the researcher or research support person (either in person or in the supplied postage paid envelope).

What is the purpose of the study?

There has been very little research focusing on the role of personal values within caregiving and how these relate to motivations to provide care, and perceived challenges and gains that caregivers experience. These will add to knowledge in order that we achieve five goals:

1. To identify issues that are important to caregivers through the use of interview and photographs.
2. To help caregivers to reflect, record and think about their values, challenges, gains and motivation.
3. To inform future caregiver research.
4. To inform the future development of interventions to enhance caregiver wellbeing.
5. To gather information to bring to the attention of politicians and other decision makers to benefit support for caregiving.

Invitation

We would like to invite you to take part in the interview regarding your experience as someone who provides care and support for a family member or friend who is diagnosed with a long term or chronic illness or disabling condition, for example: cancer, stroke, Alzheimer's disease, Parkinson's disease, Multiple Sclerosis, brain injury.

If I agree to take part, what will I have to do?

If you take part in this study you will be invited to firstly take photos that you think show your experience of caregiving over a period of 2 weeks, using a provided disposable camera. Following this you will invited to take part in an interview with the Researcher which will take place at Bangor University. The interview will ask you consider your experiences, thoughts and feelings, using the photos you have taken, as prompts. The interview will involve a discussion of the photos and also the completion of a questionnaire.

Interview will take from 1.5 to a maximum of 3 hours, with breaks and refreshment provided and available on request. Interviews will be recorded. Your identity will not be available from the data collected (paper, recordings and photos) as you will be allocated a personal code. All data will be stored securely, and the digital recordings destroyed after the interviews have been transcribed. All data is seen only by the Researcher and his Supervisory team.

Payment:

You will receive **£7 per hour** for taking part in the study. Expense forms will also be provided at the interview if you require payment of any travel and respite costs.

Findings of the study:

If you would like to receive information about the study findings please tick the box in the consent form and a summary will be sent to you once the study is completed.

Risks and benefits of participating:

There are no known risks associated with this study. In the unlikely event that taking part causes you any distress or raises any further questions about your situation, the Researcher will provide you with information about local and national organizations which can provide support. There are potential long-term benefits of participation as your contribution may help improve caregiver- care recipient services.

Do you have to participate?

Taking part in this study is entirely voluntary and you may withdraw from the study at any point without providing a reason.

Confidentiality:

Information collected in this study will be completely confidential: your name will not be on written or recorded materials. Each participant will be identified using a unique code to ensure they are completely unidentifiable to anyone outside the research team.

Who is organising this study?

This study is being carried out by Mikołaj Zarzycki as part of his PhD research which is part of a large EU funded ENTWINE project supporting research in informal caregiving. It is supervised by Professor Val Morrison and Dr Diane Seddon from Bangor University.

Who has reviewed the ethics of this study?

This study has been reviewed by the Bangor University, School of Psychology Research Ethics and Governance Committee.

Consent

If you would like to take part in this study please sign and return the attached consent form with the completed questionnaire and Photovoice consent forms as applicable.

Contacts:

If you would like any further information about the study, please feel free to contact the researcher or supervisor:

Mikołaj Zarzycki: m.zarzycki@bangor.ac.uk; 01248382194

Prof Val Morrison (supervisor): v.morrison@bangor.ac.uk

Complaints:

If you have any complaints about the study, please contact:

Prof John Parkinson, Head of School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS

Appendix C7 – Questionnaire

Thank you for taking the time to participate in this study. Please ensure you have read and fully understood the information sheet and signed the consent form. Please try to answer all the questions honestly and according to your present situation. The information that you provide will be kept completely confidential and the data will be coded so that you are unidentifiable.

Demographic questions.

Please tick the appropriate box.

Gender:

Male [ ]

Female [ ]

Age ___________

Ethnic Group:

White British [ ]
Other White [ ]
European [ ]
Black or Black British [ ]
African [ ]
Asian Other [ ]
Other ethnicity [ ]

Main diagnosis of the person you care if you are caregiver or your diagnosis if you are care receiver

Stroke [ ]
Cancer [ ]
Alzheimer’s disease [ ]
Parkinson’s disease [ ]
Multiple Sclerosis [ ]
Brain injury [ ]
Multiple diagnoses [ ]
Other please specify _____________________

Relationship to the person you care for / you are cared by ____________________

How long have you been caring for this person/How long have you needed informal care: _______________

Appendix C8 - Consent form

Title of Project:

An exploration of values, motivation, and perceived challenges and gains amongst informal caregivers

Name of Researchers: Prof Val Morrison and Mikołaj Zarzycki

	Please Tick
I confirm that I have read and fully understood the information sheet provided	☐
I confirm that I have had the opportunity to ask any questions.	☐
I understand that my participation in this study is completely voluntary and that that I have the right to withdraw at any time without having to provide a reason.	☐
I agree to take part in the interview and be recorded.	☐
I would be happy and give my permission to hear about being part of other studies conducted by the Researchers that might be carried out in the future.	☐
I would like to receive a summary of the findings in 2020 upon study completion:	☐

____
Name

____

____

____
Address

Phone ________________ ___________ ________________
Date Signature

____
Email

Please sign and return with the completed questionnaire in the pre-paid envelope provided or research themselves. You will then receive a postcard or phone call confirming the venue, date and time of the interview.

Appendix C9 - Informed Consent Form for Photovoice Participants

Title of Project:

An exploration of values, motivation, and perceived challenges and gains amongst informal caregivers

Name of Researchers: Prof Val Morrison and Mikołaj Zarzycki

As a participant in Photovoice, you have the following rights and responsibilities:

Rights:

- You have the right to express your views and experiences during the interview.
- You have the right to choose the photographs you would like to discuss in the interview.
- You have the right to choose the photographs that will be used in the research.
- You have the right to change your mind about using any of your photographs.

Responsibilities:

- Stick to Photovoice guidelines (provided in a separate sheet), i.e., stay safe and be respectful to others.
- You have the responsibility to ask friends or family if they consent to being in a photograph, before taking the photo.

Do you agree to the above rights and responsibilities as a participant of the Photovoice study?

___ Yes

___ No

You may refuse to participate or withdraw from the project at any time without any risk to yourself. If this occurs, you are free to choose between destroying your contributions to the study or releasing them for use without your participation.

Code/Name of photographer

____

Signature

____

Date

____

Appendix C10 - Photovoice Photography General Release Form

Title of Project

An exploration of values, motivation, and perceived challenges and gains amongst informal caregivers

Name of Researchers: Prof Val Morrison and Mikołaj Zarzycki

I, ______________________, give permission for Bangor University to use my photographs developed during the study ‘An exploration of values, motivation, and perceived challenges and gains amongst informal caregivers’. They are free to use the photographs for project related reports, exhibits and presentations.

Signature

____

Date

____

Appendix C11 - Photovoice Photography Subject Consent Form

Title of Project:

An exploration of values, motivation, and perceived challenges and gains amongst informal caregivers

Name of Researchers: Prof Val Morrison and Mikołaj Zarzycki

You are invited to have your picture taken by one of the photographers involved with the study (title seen above). This Photovoice project is funded by the Bangor University and European Union and has five goals:

1. To identify issues that are important to caregivers through the use of interview and photographs.
2. To help caregivers to reflect, record and think about their values, challenges, gains and motivation.
3. To inform future caregiver research.
4. To inform the future development of interventions to enhance caregiver wellbeing.
5. To gather information to bring to the attention of politicians and other decision makers to benefit support for caregiving.

By signing my name below, I understand and agree that unless otherwise stated in writing, Bangor University assumes that permission is granted to use my photographs for project related reports, exhibits and presentations that are likely to result from this project.

Please sign this form if you agree to have your photograph taken by a participant of Photovoice.

If you would like a copy of the photograph taken of you, please write down your address:

________________________	______________________________
Subject Name	Name of Photographer

____

Signature

____

Date

Appendix C12 – Photovoice guidelines

PHOTOVOICE GUIDELINES

Stay Safe

- Don’t take any risks.
- Don’t go anywhere you wouldn’t usually go, or do anything you wouldn’t usually do.
- Be aware of what’s around you.

Be Respectful

- Always ask first, even if this means missing the perfect shot.
- You must have permission before taking pictures of people.
- Don’t upset people. This just gives the whole project a bad name.

Large Crowds, Landscape or Scenery

- You do not need a Subject Consent Form if people are too small to be recognizable.
- It is still a good idea to ask permission before taking a picture of private property (someone’s house or yard, for example).

For Pictures with People

- Have your subjects sign a Subject Consent Form before taking any pictures.
- Do not take pictures of people who are “in private”, such as through a window into their home.
- Ask yourself, ‘Would I mind if someone took a picture of me in this situation?’
- Remember to offer the person a copy of the picture.

Appendix C13 – Photovoice tips for Pictures with People

1	Friendly Greeting	‘Hello there. How are you?’
2	Tell **briefly** about Photovoice	‘I’m a participant in a study held at Bangor University which is trying to get a better understanding of caregivers and care recipients experience through their photographs. I want people to know about what matters to me. The picture will be used for scientific purposes only.’
3	Ask permission ***If person says, “No”, accept this, thank them, and move on!***	‘Can I take a picture of you _______? ‘Can I take a picture of your _______?
4	Have person sign a Subject Consent Form, if needed	‘Before taking your picture, I’ll need you to sign this form.’
5	Offer person a copy of the picture.	‘If you want to, I can give you a copy of the picture.’
6	Thank the person.	‘Thanks for letting me take that picture. Your contribution may help improve understanding of caregiver experience.’

D1 Appendix – Eligibility survey

1. **Please select from the list below the language you would like to take this survey in.**

   ☐ English

   ☐ Dutch

   ☐ Greek

   ☐ Italian

   ☐ Polish

   ☐ Swedish

   ☐ German

   ☐ Hebrew

2. **Please select from the list below your current country of residence.**

   ☐ UK

   ☐ The Netherlands

   ☐ Greece

   ☐ Italy

   ☐ Ireland

   ☐ Poland

   ☐ Sweden

   ☐ Germany

   ☐ Israel

3. **How did you hear about this study?**

   ☐ Flyer/leaflet or poster display (please provide location)

   ☐ A Family member or friend

   ☐ Health care provider

   ☐ Facebook post/group

   ☐ Twitter post

- ☐ Other social media
- ☐ Email
- ☐ Radio
- ☐ Newspaper
- ☐ Word of mouth
- ☐ Caregiver or patient support group
- ☐ ENTWINE study website
- ☐ Other

Before we can tell you more about the study, we have to find out whether you are eligible to participate. In order to find out, please answer the following questions. By filling in the eligibility check and clicking on continue, you agree that the data of the eligibility screening can be used for study purposes.

4. **Are you 18 years or older?**
   - ☐ No *(Unfortunately, you are not eligible to participate in this study. We would like to thank you very much for your time and effort.)*
   - ☐ Yes

5. **Which of the following statements best describes your caregiving or care receiving experiences?**
   - ☐ I provide care for a family member or a friend with a chronic health condition, disability or any other care need that is 18 years old or over.
   - ☐ I receive care from a family member or a friend, that is 18 years old or older, due to my chronic health condition, disability or any other care ne
   - ☐ None of the above. *(Unfortunately, you are not eligible to participate in this study. We would like to thank you very much for your time and effort.)*

Participation in the study is entirely voluntary, but because of scientific guidelines, we need to ask you for your digital consent before taking part. To help you decide whether you want to take part in the study or not, we will first explain how the study is conducted and what is expected from you. We kindly ask you to read this information carefully.

If you decide to participate in the study after reading the information, you can give us digital consent. This can be done online and will only take a minute. Of course, you may also decide you do not want to be part of the research. Please feel free to decide either way.

D2 Appendix - ENTWINE-iCohort Survey

ENTWINE

INFORMAL CARE

The European Training Network on Informal Care

ENTWINE-iCOHORT CAREGIVER SURVEY

1. **Would you like to invite the person you provide care for to participate in this study?**
   - ☐ Yes. Email address: ________________
   - ☐ Yes, but I would like to provide their email at a later date.
   - ☐ Yes, but they do not have an email address.
   - ☐ No

This study is being carried out by Bangor University (UK), University Medical Center of Groningen (The Netherlands), National Institute for Health and Science on Ageing (Italy), Bar-Ilan University (Israel) and Uppsala University (Sweden).

Instructions for this questionnaire:

- If you read ‘your loved one’, then the question refers to the person for whom you are a caregiver.
- Read each question through completely before answering.
- An “Other” option is provided in case you believe that the response options do not describe your situation or the situation of your loved one adequately.
- If you need to take breaks while completing the survey, you can close the survey window at any point and your responses will be automatically saved. We recommend that you fill in this questionnaire using a laptop or tablet.

This questionnaire starts with some questions relating to you.

2. **How old are you?**

_______ years.

3. **What is your gender?**
   - ☐ Female
   - ☐ Male
   - ☐ Non-binary / third gender
   - ☐ Prefer to self describe:
   - ☐ Prefer not to say

4. **Which city/town do you live in?**

____

5. **Is your home located in?**
   - ☐ central city/area
   - ☐ peripheral area in the city
   - ☐ rural area

6. **Please indicate the highest level of education you have achieved**
   - ☐ Primary
   - ☐ Secondary
   - ☐ Post-secondary vocational education (e.g., further education college, apprenticeships etc.)
   - ☐ Post secondary academic education (e.g., university)
   - ☐ Not listed or other

7. **What is your marital status?**
   - ☐ Single (never married) (skip to question 9)
   - ☐ Married
   - ☐ In a civil union/domestic partnership
   - ☐ Divorced (skip to question 9)
   - ☐ Widowed (skip to question 9)
   - ☐ Other (specify) _______________

8. **For how long have you been in this relationship?**

   Years _________ Months________

9. **Do you have children?**

If you answer "yes", please specify how many children you have.

- ☐ No (skip to question 12)
- ☐ Yes. I have _____child(ren)

10. **Do you have children under 18 years of age?**

    If you answer "yes", please specify how many children under 18 years old you have.

    - ☐ No
    - ☐ Yes. I have _______ children under 18 years of age.

11. **Do your children live in your home?**

    If you answer "yes", please specify how many children live in your home.

    - ☐ No
    - ☐ Yes. _____child(ren) live in my home

12. **Do you have siblings?**

If yes, please provide the number of living siblings.

☐ No
☐ Yes _____ sibling(s)

13. **Are your parents alive?**

If yes, please detail how many of your parents are still alive.

☐ No
☐ Yes ______parent(s)

14. **Are you currently employed or self-employed (working for pay)?**

☐ No
☐ Yes

15. **During the COVID-19 pandemic have you lost your job?**

☐ No
☐ No, but I started to work from home as a result of the COVID-19 situation
☐ Yes, permanently
☐ Yes, temporarily

16. **When you compare your financial situation before COVID-19 pandemic and now would you say it has become better worse or remained the**

☐ Better
☐ The same
☐ Worse
☐ Do not know

Skip to question 20 if you answered "no" to question 14

17. **Are you currently working full-time (e.g., according to your employment contract)?**

☐ No. I work part-time: _______hours per week.
☐ Yes, I work full time: _______hours per week.

18. **After any taxes and contributions, what is your average monthly income from employment?**

Please include any additional or extra or lump sum payment, such as bonuses, 13 month, Christmas or Summer pays.

- ☐ _____________ (skip to question 20)
- ☐ I prefer not to answer this question.

19. Please indicate your monthly income level after taxes and contributions.[5]

Please include any additional or extra or lump sum payment, such as bonuses, 13 month, Christmas or Summer pays.

- ☐ Less than £800
- ☐ Between £800 and 1500
- ☐ Between £1500 and £4000
- ☐ More than £4000
- ☐ Prefer not to answer this question

20. What is your religion, if any?[6]

- ☐ Protestant
- ☐ Roman Catholic
- ☐ Eastern Orthodox
- ☐ Islam
- ☐ Jewish
- ☐ Buddhist
- ☐ Hindu
- ☐ Other (specify)
- ☐ I am not religious (skip to question 22)
- ☐ Prefer not to say

21. What is the importance of religion in your life?

- ☐ Not important at all
- ☐ Not too important
- ☐ Fairly important
- ☐ Very important

---

[5] The income brackets provided in this question were applied in the UK. Income brackets for other countries were adjusted to reflect differences in average incomes of the population. These values were based on the Survey of Health, Ageing and Retirement in Europe (SHARE).

[6] Question not asked in Italy, Sweden and the Netherlands due to ethical reasons

22. What are your ethnic/family origins?[7]

Choose between sections A-E and select only one of the options that best describes your ethnic background.

A. European

- ☐ British or Irish
- ☐ Scandinavian
- ☐ Eastern and Central European
- ☐ Mediterranean
- ☐ Any other European background, please write in:

B. Asian

- ☐ South Asian
- ☐ Chinese
- ☐ Japanese
- ☐ Malaysian, Vietnamese or Filipino
- ☐ Any other Asian background, please write in:

C. Black

- ☐ Caribbean
- ☐ African
- ☐ Any other Black background, please write in:

D. Other ethnic group

- ☐ Jewish
- ☐ Arab
- ☐ Other ethnic group, please write in:
- ☐ Mixed/Multiple ethnic groups, please write in:

- ☐ E. Prefer not to say

23. How would you describe your national identity?

I am a national/citizen of:

____

---

[7] Question not asked in Italy, Sweden and the Netherlands due to ethical reasons

24. Did you migrate to the country you live in?

- ☐ No (skip to question 26)
- ☐ Yes

25. In what country were you born?

____

26. Did any of your parents migrate to the country you live in?

- ☐ No (skip to question 29)
- ☐ Yes

27. In what country was your father born?

____

28. In what country was your mother born?

____

29. How many people aged 18 or over do you provide informal care for?

____

30. Do you have any of the following?

Please select all that apply.

- ☐ A physical impairment or disability
- ☐ Sight or hearing loss
- ☐ A mental health problem or illness
- ☐ A learning disability or difficulty
- ☐ A long-standing illness
- ☐ Multimorbidity
- ☐ Other (please specify)
- ☐ None of the above

31. **Have you been diagnosed with COVID-19?**
    - ☐ No
    - ☐ Yes, but I was not admitted to a hospital or intensive care unit
    - ☐ Yes, and I was admitted to a hospital but not an intensive care unit
    - ☐ Yes, and I was admitted to an intensive care unit
    - ☐ Prefer not to say

Let's focus on the adult for whom you have been providing the most assistance. From now on, we will refer to the person you care for as "your loved one".

32. **How old is your loved one?**

____

33. **What is the gender of your loved one?**
    - ☐ Female
    - ☐ Male
    - ☐ Non-binary / third gender
    - ☐ Prefer to self describe:
    - ☐ Prefer not to say

34. **Has your loved one been diagnosed with COVID-19?**
    - ☐ No
    - ☐ Yes, but they were not admitted to a hospital or intensive care unit
    - ☐ Yes, and they were admitted to a hospital but not an intensive care unit
    - ☐ Yes, and they were admitted to an intensive care unit
    - ☐ Prefer not to say

35. **What health condition(s) has your loved one been diagnosed with?**

Please select all that apply.

- ☐ A heart attack including myocardial infarction or coronary thrombosis or any other heart problem including congestive heart failure
- ☐ High blood pressure or hypertension
- ☐ High blood cholesterol
- ☐ A stroke or cerebral vascular disease
- ☐ Diabetes or high blood sugar
- ☐ Chronic lung disease such as chronic bronchitis or emphysema
- ☐ Cancer (please specify the type of cancer if known).

- ☐ Stomach or duodenal ulcer, peptic ulcer
- ☐ Parkinson disease
- ☐ Cataracts
- ☐ Hip fracture
- ☐ Other fractures
- ☐ Alzheimer's disease, dementia, organic brain syndrome, senility or any other serious memory impairment, please specify:
- ☐ Multiple sclerosis
- ☐ Rheumatoid Arthritis
- ☐ Osteoarthritis, or other rheumatism
- ☐ Chronic kidney disease
- ☐ Traumatic brain injury
- ☐ HIV/AIDS
- ☐ Other condition(s) _________
- ☐ They have not been diagnosed with any conditions (skip to question 38)

36. Which one of these health conditions do you think causes the most limitations to your loved one?

____

37. How long has your loved one been living with this health condition?

Years ______ Months_____

38. What is your relationship with your loved one?

- ☐ My loved one is my:
- ☐ spouse / partner
- ☐ mother or father
- ☐ mother-in-law or father-in-law
- ☐ daughter or son
- ☐ grandmother / grandfather
- ☐ sibling
- ☐ another family member
- ☐ friend
- ☐ acquaintance / neighbour / other non-relative
- ☐ Other, please specify below.

39. Do you share a household with your loved one?

- ☐ No
- ☐ Yes (skip to question 46)

40. Where does your loved one live?

☐ In their own home
☐ In someone else's home
☐ In an assisted living facility or other residential setting where some care is provided
☐ In a nursing care or long-term care facility (skip to question 42)

41. Indicate the option that best describes your loved one's living arrangement:

Please select all that apply.

☐ Alone
☐ With their children
☐ With their partner
☐ With paid carers
☐ With others, please specify

42. Which city/town does your loved one live in?

____

43. Is the place where your loved one lives, located in a:

☐ central city/area
☐ peripheral area in the city
☐ rural area

44. How do you reach the place where your loved one lives?

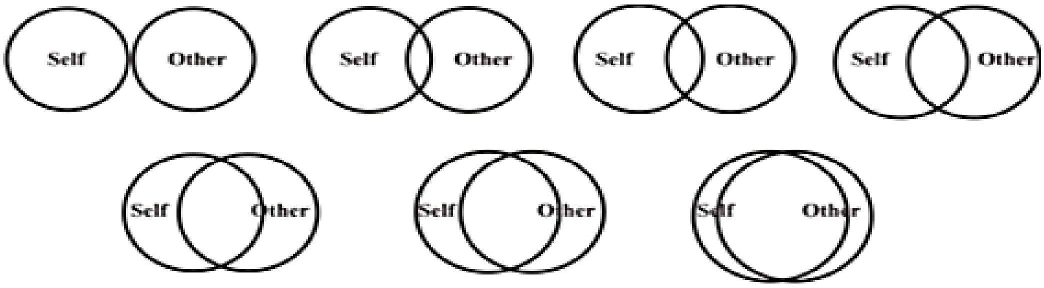
☐ I walk to their home
☐ I cycle to their home
☐ I drive to their home
☐ I use public transportation (bus or train)
☐ If Other, please specify

45. How far is your home from the place where your loved one lives?

☐ less than 15 minutes
☐ 15 to 30 minutes
☐ 30 to 60 minutes
☐ 60 to 90 minutes
☐ 90 to 120 minutes
☐ More than 120 minutes

46. **Inclusion of Other in the Self Scale (IOS)** (Aron et al., 1992)

Below there are seven pairs of circles: the level of overlap between the circles indicates how close you feel to your loved one. The greater the overlap, the closer you feel to your loved one. Please indicate the picture that best describes your relationship with your loved one.



47. **Does your loved one have any difficulty with these activities?** (Katz, 1983)

Please select all that apply.

☐ Dressing, including putting on shoes and socks
☐ Walking across a room
☐ Bathing or showering
☐ Eating, such as cutting up their food
☐ Getting in or out of bed
☐ Using the toilet, including getting up or down
☐ None of these

48. **How long have you been providing informal care to your loved one?**

I*nformal care is any care or help provided to older people (family or otherwise), working age adults, and young people and children with disability as well as people living with mental health problems. Please note, this does not include care provided by paid care professionals.*

☐ Less than a month: ________ week(s).
☐ Less than a year: _______ month(s).
☐ More than a year: _______ year(s).

Please fill in the following 4 questions in relation to the last week OR on a typical week if last week was a holiday, or if you were away, or ill, etc.

A limit of 126 hours has been set for the number of hours of care that you provide each week. The purpose of this limit is not to undervalue or underestimate the care that you provide. This limit has been set to allow you time (6 hours per day) for basic needs such as resting/sleeping and doing non-care related tasks.

49. **During the last week, on how many days did you provide care to your loved one?**

    - ☐ 0 days
    - ☐ 1 day
    - ☐ 2 days
    - ☐ 3 days
    - ☐ 4 days
    - ☐ 5 days
    - ☐ 6 days
    - ☐ 7 days

50. **During the last week, how much time did you spend on household activities and tasks that you would not have had to perform if your loved one was in good health, or if they could have done them independently?**

For example preparing food, cleaning, washing, ironing, sewing, shopping, and gardening.

______hours per week.

51. **During the last week, how much time did you spend helping your loved one with their personal care?**

For example dressing/undressing, washing/showering/bathing, hair care, shaving and grooming, and going to the toilet.

_________hours per week.

52. **During the last week, how much time did you spend providing practical support to your loved one that would not have had to be performed if they were in good health, or if they could have done it independently?**

For example eating and drinking, moving inside or outside the house (including assistance with walking or using a wheelchair), visiting family or friends, accompany to healthcare visits (e.g. doctor appointments), filling prescriptions at the pharmacy, help taking medications, and taking care of financial matters (e.g. paying the bills or managing healthcare insurance).

_____ hours per week.

53. **During the last week, how much time did you spend on providing emotional support to your loved one that would not have had to be provided**

For example help to cope with pain, disability, and discomfort, anxiety, worry, and loneliness.

_____hours per week.

54. **Due to COVID-19 the hours of emotional support you provide have:**

- ☐ Increased by ______ hour(s) per week
- ☐ Decreased by ____ hour(s) per week
- ☐ Stayed the same

55. Due to COVID-19 the hours of practical support you provide have:

- ☐ Increased by ____ hour(s) per week
- ☐ Decreased by ____ hour(s) per week
- ☐ Stayed the same

56. Due to COVID-19 the hours of personal care you provide have:

- ☐ Increased by hour(s) per week
- ☐ Decreased by hour(s) per week
- ☐ Stayed the same

57. Besides your care or support, does she/he also receive care from other informal caregivers?

- ☐ No, I am the only informal caregiver (skip to question 60)
- ☐ Yes, from ________________________________ [number] other informal caregivers

58. In the past week, how many hours of care did these informal caregiver(s) provide for your loved one?

- ☐ They have not provided any care.
- ☐ They have provided hours of care.
- ☐ Do not know

59. Do you consider yourself to be the person who provides most of the informal care for your loved one?

- ☐ No
- ☐ Yes (skip to question 61)

60. Who would you consider to be the person who provides most of the informal care for your loved one? Their:

- ☐ Spouse / Partner
- ☐ Child
- ☐ Parent
- ☐ Sibling
- ☐ Daughter- / Son-in-law
- ☐ Uncle / Aunt
- ☐ Nephew/ Niece

☐ Cousin
☐ Friend
☐ Neighbour
☐ Other, please specify

61. Have you previously provided informal care for another person?

☐ No
☐ Yes

Now we want to ask you about the services that your loved one may have received from paid care worker(s), sitting services and overnight care.

62. Over the past three months, has your loved one been provided with home care also by one or more paid care workers?

☐ No (skip to question 73)
☐ Yes

63. How many paid care workers are involved with your loved one's home care?

☐ 1
☐ 2 (skip to question 69)
☐ 3 (skip to question 69)
☐ 4 (skip to question 69)
☐ More than 4 (skip to question 69)

64. Was the paid worker a migrant care worker?

"Migrant worker" refers to a person who is employed in a country that they migrated to. This includes not only people who migrated for the purpose of employment, but also those who migrated for other reasons (eg., family or education) and then gained employment at a later date.

☐ No (skip to question 67)
☐ Yes
☐ Do not know (skip to question 67)

65. Please fill in the follow table based on the situation of the migrant care worker

Employed on a live-in basis?	**Gender**	**Age**	**Level of education**	**Marital status**

No	Female	18-24	Primary	Single (never married)
Yes	Male	25-34	Secondary	Married
	Non-binary /third gender	35-44	Post-secondary vocational education (e.g., further education college, apprenticeships etc.)	In a civil union/domestic partnership
	Do not know	45-54	Post secondary academic education (e.g., university)	Divorced
		55-64	Not listed or other	Widowed
		65-74	Do not know	Do not know
		75+		
		Do not know		

66. **What is the nationality of the migrant care worker?**

    They are a national/citizen of:

    ____

Skip to question 73 if you answered "yes" to question 64

67. **Please fill in the follow table based on the situation of the paid care worker**

Employed on a live-in basis?	**Gender**	**Age**	**Level of education**	**Marital status**
No	Female	18-24	Primary	Single (never married)

Yes	Male	25-34	Secondary	Married
	Non-binary /third gender	35-44	Post-secondary vocational education (e.g., further education college, apprenticeships etc.)	In a civil union/domestic partnership
	Do not know	45-54	Post secondary academic education (e.g., university)	Divorced
		55-64	Not listed or other	Widowed
		65-74	Do not know	Do not know
		75+		
		Do not know		

68. Does the paid care worker have a migration background?

"Migration background" refers to a person who has:

(a) migrated into their present country of residence; and/or

(b) previously had a different nationality from their present country of residence; and / or

(c) at least one of their parents previously entered their present country of residence as a migrant.

☐ No
☐ Yes
☐ Do not know

Skip to question 73 if you answered “no” or “do not know” to question 64

69. Were any of these paid workers a migrant worker?

“Migrant worker" refers to a person who is employed in a country that they migrated to. This includes not only people who migrated for the purpose of employment, but also those who migrated for other reasons (eg., family or education) and then gained employment at a later date.

- ☐ No (skip to question 72)
- ☐ Yes
- ☐ Do not know (skip to question 72)

70. Please fill in a separate row in the table for each individual worker. "Migration background" refers to a person who has:

(a) migrated into their present country of residence; and/or

(b) previously had a different nationality from their present country of residence; and / or

(c) at least one of their parents previously entered their present country of residence as a migrant.

	Employed on a live-in basis?	**Migrant worker?**	**Migration background ?**	**Gender**	**Age**	**Level of education**	**Marital status**
Care worker n. 1	No Yes	No Yes Do not know	No Yes Do not know	Female Male Non-binary /third gender Do not know	18-24 25-34 35-44 45-54 55-64 65-74 75+ Do not know	Primary Secondary Post-secondary vocational education (e.g., further education college, apprenticeships etc.) Post secondary academic education (e.g., university)	Single (never married) Married In a civil union/domestic partnership Divorced Widowed Do not know

						Not listed or other Do not know	
Care worker n. 2	No Yes	No Yes Do not know	No Yes Do not know	Female Male Non-binary /third gender Do not know	18-24 25-34 35-44 45-54 55-64 65-74 75+ Do not know	Primary Secondary Post-secondary vocational education (e.g., further education college, apprenticeships etc.) Post secondary academic education (e.g., university) Not listed or other Do not know	Single (never married) Married In a civil union/domestic partnership Divorced Widowed Do not know
Care worker n. 3	No Yes	No Yes Do not know	No Yes Do not know	Female Male Non-binary /third gender Do not know	18-24 25-34 35-44 45-54 55-64 65-74 75+ Do not know	Primary Secondary Post-secondary vocational education (e.g., further education college, apprenticeships etc.) Post secondary academic education (e.g., university) Not listed or other Do not know	Single (never married) Married In a civil union/domestic partnership Divorced Widowed Do not know

Care worker n. 4	No Yes	No Yes Do not know	No Yes Do not know	Female Male Non-binary /third gender Do not know	18-24 25-34 35-44 45-54 55-64 65-74 75+ Do not know	Primary Secondary Post-secondary vocational education (e.g., further education college, apprenticeships etc.) Post secondary academic education (e.g., university) Not listed or other Do not know	Single (never married) Married In a civil union/domestic partnership Divorced Widowed Do not know

71. What is the nationality of the migrant care worker(s)?

They are a national/citizen of:

Care worker n. 1 _________

Care worker n. 2 _________

Care worker n. 3 _________

Care worker n. 4 _________

Skip to question 73 if you answered “yes” to question 69

72. Please fill in a separate row in the table for each individual worker. "Migration background" refers to a person who has:

(a) migrated into their present country of residence; and/or

(b) previously had a different nationality from their present country of residence; and / or

(c) at least one of their parents previously entered their present country of residence as a migrant.

	Employed on a live-in basis?	**Migration background?**	**Gender**	**Age**	**Level of education**	**Marital status**
Care worker n. 1	No Yes	No Yes Do not know	Female Male Non-binary /third gender Do not know	18-24 25-34 35-44 45-54 55-64 65-74 75+ Do not know	Primary Secondary Post-secondary vocational education (e.g., further education college, apprenticeships etc.) Post secondary academic education (e.g., university) Not listed or other Do not know	Single (never married) Married In a civil union/domestic partnership Divorced Widowed Do not know
Care worker n. 2	No Yes	No Yes Do not know	Female Male Non-binary /third gender Do not know	18-24 25-34 35-44 45-54 55-64 65-74 75+ Do not know	Primary Secondary Post-secondary vocational education (e.g., further education college, apprenticeships etc.) Post secondary academic education (e.g., university) Not listed or other	Single (never married) Married In a civil union/domestic partnership Divorced Widowed Do not know

					Do not know	
Care worker n. 3	No Yes	No Yes Do not know	Female Male Non-binary /third gender Do not know	18-24 25-34 35-44 45-54 55-64 65-74 75+ Do not know	Primary Secondary Post-secondary vocational education (e.g., further education college, apprenticeships etc.) Post secondary academic education (e.g., university) Not listed or other Do not know	Single (never married) Married In a civil union/domestic partnership Divorced Widowed Do not know
Care worker n. 4	No Yes	No Yes Do not know	Female Male Non-binary /third gender Do not know	18-24 25-34 35-44 45-54 55-64 65-74 75+ Do not know	Primary Secondary Post-secondary vocational education (e.g., further education college, apprenticeships etc.) Post secondary academic education (e.g., university) Not listed or other Do not know	Single (never married) Married In a civil union/domestic partnership Divorced Widowed Do not know

73. **Besides your care or support, does your loved one visit a daycare facility or a residential or nursing home?**
    - ☐ No
    - ☐ Yes, for ___ hour(s) during the last week.

The next questions will ask about the services that you, the caregiver, may have used.

74. **Have you received any of the following services in the past six months?**
    - ☐ Information about the disease that the loved one has.
    - ☐ Coordination services providing information and advice about the type of help, support and benefits that is available to carers and how to access it (e.g. information centers, case (or care) managers, advice or guidance from a physician or social worker.
    - ☐ Training to help carers develop the skills they need to care and cope with the burden of care
    - ☐ Counselling (i.e. supportive and social counselling, etc.).
    - ☐ Self-help or support group
    - ☐ Formal standardized assessment of your needs or caring situation
    - ☐ Reconciliation of caring and employment (e.g. flexible work arrangements and paid and/or unpaid care leaves from work).
    - ☐ In-home respite care (temporary or short-term care provided at home to give rest or relief to informal caregivers from the tasks of caregiving).
    - ☐ Out-of-home respite care (e.g. day-care services and temporary stay at a residential or nursing home).
    - ☐ None of them (skip to question 79)

For question 75 and 76, only complete the options that correspond to the options you selected in question 74.

75. **In a typical month, how many times do you use the following service(s)?**

    - ☐ Information about the disease that the loved one has _______________

    - ☐ Coordination services providing information and advice about the type of help, support and benefits that is available to carers and how to access it (e.g. information centers, case (or care) managers, advice or guidance from a physician or social worker) _______________

- ☐ Training to help carers develop the skills they need to care and cope with the burden of care. _______________

- ☐ Counselling (i.e. supportive and social counselling, etc.) _______________

- ☐ Self-help or support group _______________

- ☐ In-home respite care (temporary or short-term care provided at home to give rest or relief to informal caregivers from the tasks of caregiving) _______________

- ☐ Out-of-home respite care (e.g. day-care services and temporary stay at a residential or nursing home). _______________

76. Which of these services have you received online?

Please select all that apply.

- ☐ Information about the disease that the loved one has.
- ☐ Coordination services providing information and advice about the type of help, support and benefits that is available to carers and how to access it (e.g. information centers, case (or care) managers, advice or guidance from a physician or social worker).
- ☐ Training to help carers develop the skills they need to care and cope with the burden of care.
- ☐ Counselling (i.e. supportive and social counselling, etc.).
- ☐ Self-help or support group.
- ☐ None

77. Given the COVID-19 situation, do you still have access to the usual support services you receive as a caregiver?

- ☐ No (skip to question 79)
- ☐ Yes (skip to question 79)
- ☐ Yes, but I have to receive some of these services online due to COVID-19

78. Please indicate which of the following services you receive online due to COVID-19:

Please select all that apply.

- ☐ Information about the disease that the loved one has.
- ☐ Coordination services providing information and advice about the type of help, support and benefits that is available to carers and how to access it (e.g. information centers, case (or care) managers, advice or guidance from a physician or social worker).

- ☐ Training to help carers develop the skills they need to care and cope with the burden of care.
- ☐ Counselling (i.e. supportive and social counselling, etc.).
- ☐ Self-help or support group.
- ☐ If Other please specify

79. Do you receive any of the following benefits because of your caregiving role?

- **Cash benefits (e.g. carer allowance, carer's benefit, care wage, cash for care, paid kin caregiver, bonuses, etc)**

  - ☐ No
  - ☐ Yes. I receive ____ per month.

- **Financial compensation during care leave (e.g. care-leave benefits, career break compensation, family hospice leave grant, income replace**

  - ☐ No
  - ☐ Yes. I receive _____ per month.

- **Tax benefits such as exemptions, deductions, and credits (e.g. council tax reduction, deductions from income tax, etc.)**

  - ☐ No
  - ☐ Yes

- **Coverage of social or pension contributions (e.g. contributions are wholly or partly paid by the government or insurance).**

  - ☐ No
  - ☐ Yes

- **Carer/caregiver credits (i.e. pension credits received for providing care).**

  - ☐ No
  - ☐ Yes

- **Health insurance**

  - ☐ No
  - ☐ Yes

80. **Motivations in Elder Care Scale (MECS)** (Lyonette & Yardley, 2003)

The following statements describe some of the reasons why people begin caring for a relative or friend. Please answer each question by choosing the option which best describes your own situation.

	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree
I felt that I had no choice but to care for my loved one:					
I would feel guilty if I didn't care for the loved one:					
The loved one expected me to care for them:					
I felt that people would disapprove if I didn't care for the loved one:					
It's part of my nature to care for others:					
I felt it was my duty to care for the loved one:					
I wanted to make sure the loved one was safe:					
Caring for the loved one was an automatic decision:					
I do not/did not want the loved one to go into a home:					
I wanted to provide care for the loved one myself:					
Caring for the loved one is a way of living up to my principles:					
The loved one was gradually becoming more dependent on me:					
I felt that I had a responsibility towards the loved one:					

81. **Partner-Specific Communal Motivation scale (CMS)** (Lemay & Neal, 2013)

Keeping in mind your loved one, indicate the extent to which each statement applies to you.

	Not at all								Extremely
Helping my loved one is a high priority for me.	1	2	3	4	5	6	7	8	9
I could easily put my loved one's needs out of my thoughts.	1	2	3	4	5	6	7	8	9
I care for my loved one.	1	2	3	4	5	6	7	8	9
I care about my loved one's well-being.	1	2	3	4	5	6	7	8	9
I could easily accept not helping my loved one.	1	2	3	4	5	6	7	8	9
I would sacrifice very much to help my loved one.	1	2	3	4	5	6	7	8	9
I would incur a large cost in order to help my loved one.	1	2	3	4	5	6	7	8	9
I care for my loved one's needs.	1	2	3	4	5	6	7	8	9
I would go out of my way to help my loved one.	1	2	3	4	5	6	7	8	9
I would be reluctant to sacrifice for my loved one.	1	2	3	4	5	6	7	8	9

82. **Willingness to care scale (WTC)** (Abell, 2001)

Caregiving can be a demanding and sometimes overwhelming experience. Caregivers may differ in the tasks they feel able and/or willing to perform.

Being able to perform a task means that you believe you could do it if necessary. Being willing to perform a task means that you feel you would do it if it had to be done.

For example: I am able to change soiled sheets but I would not be completely willing to do so.

As you read the statements below, think about your loved one.

First, choose yes for each one of the tasks you feel able to do for your loved one. Second, reread the items, and choose the option which best shows how willing you are to do each one.

	Able? (No/Yes)	How willing?				
Listen to your loved one when they are sad.		1	2	3	4	5
Comfort your loved one when they are upset.		1	2	3	4	5
Help your loved one deal with anxiety about the future.		1	2	3	4	5
Hold hands when your loved one is afraid.		1	2	3	4	5
Encourage your loved one when they feel hopeless.		1	2	3	4	5
Listen to your loved one’s concerns about death or dying.		1	2	3	4	5
Help keep your loved one’s spirits up.		1	2	3	4	5
Hold your loved one when they are crying.		1	2	3	4	5
Listen to your loved one when they are angry.		1	2	3	4	5
Be patient when your loved one is disoriented or confused.		1	2	3	4	5
Take your loved one to a medical appointment.		1	2	3	4	5
Bring home the groceries for your loved one.		1	2	3	4	5
Help pay for your loved one’s medicine.		1	2	3	4	5
Prepare meals for your loved one.		1	2	3	4	5
Clean your loved one’s room or home.		1	2	3	4	5
Wash your loved one’s dishes.		1	2	3	4	5
Do your loved one’s laundry.		1	2	3	4	5
Help pay for your loved one’s food or housing.		1	2	3	4	5
Have your loved one live in your home.		1	2	3	4	5
Negotiate your loved one’s health care options with a doctor.		1	2	3	4	5
Help your loved one take medicine.		1	2	3	4	5
Change your loved one’s dirty bed sheets.		1	2	3	4	5
Help your loved one take a bath.		1	2	3	4	5
Clean up after your loved one who has lost bowel or bladder control.		1	2	3	4	5
Help your loved one eat a meal.		1	2	3	4	5

Clean up when your loved one has thrown up.		1	2	3	4	5
Turn your loved one in bed.		1	2	3	4	5
Change dressings on your loved one's sores.		1	2	3	4	5
Help your loved one in the bathroom.		1	2	3	4	5
Help your loved one move in and out of bed.		1	2	3	4	5

83. Have your thoughts and feelings about COVID-19 influenced how you feel about caregiving in terms of your willingness to care?

☐ Yes, I feel more willing to provide care for my loved one
☐ Yes, I feel less willing to provide care for my loved one
☐ No

84. The World Health Organisation-Five Well-Being Index (WHO-5)

	Over the last two weeks	All of the time	Most of the time	More than half of the time	Less than half of the time	Some of the time	At no time
1	I have felt cheerful and in good spirits	5	4	3	2	1	0
2	I have felt calm and relaxed	5	4	3	2	1	0
3	I have felt active and vigorous	5	4	3	2	1	0
4	I woke up feeling fresh and rested	5	4	3	2	1	0
5	My daily life has been filled with things that interest me	5	4	3	2	1	0

85. Caregiver GAINS scale (Pearlin, 1988)

As a result of providing care, to what extent did you:

	A lot	Somewhat	A little	Not at all
Become more sensitive to persons with disabilities?				

Get a better idea of what’s important in life?				
Become aware of inner strengths?				
Become closer to God?				
Grow as a person?				
Become closer to family?				
Gain a sense of fulfilling duty?				
Become more self confident?				
Learn to do new things?				
Make new friends?				

86. **Zarit Burden Interview (ZBI-12)** (Bedard et al., 2001)

The following is a list of statements which reflect how people sometimes feel when taking care of their loved one.

Do you feel...

	Never	Rarely	Sometimes	Quite frequently	Nearly always
That because of the time you spend with your loved one that you don’t have					
Stressed between caring for your loved one and trying to meet other					
Angry when you are around your loved one?					
That your loved one currently affects your relationship with family members					
Strained when you are around your loved one?					

That your health has suffered because of your involvement with your loved					
That you don’t have as much privacy as you would like because of your					
That your social life has suffered because you are caring for your loved					
That you have lost control of your life since your loved one’s illness?					
Uncertain about what to do about your loved one?					
You should be doing more for your loved one?					
You could do a better job in caring for your loved one?					

87. EQ-5D-5L

Please select the ONE box that best describes your health TODAY.

MOBILITY

☐ I have no problems in walking about
☐ I have slight problems in walking about
☐ I have moderate problems in walking about
☐ I have severe problems in walking about
☐ I am unable to walk about

Please select the ONE box that best describes your health TODAY.

SELF-CARE

☐ I have no problems washing or dressing myself

- ☐ I have slight problems washing or dressing myself
- ☐ I have moderate problems washing or dressing myself
- ☐ I have severe problems washing or dressing myself
- ☐ I am unable to wash or dress myself

Please select the ONE box that best describes your health TODAY.

USUAL ACTIVITIES (e.g. work, study, housework, family or leisure activities)

- ☐ I have no problems doing my usual activities
- ☐ I have slight problems doing my usual activities
- ☐ I have moderate problems doing my usual activities
- ☐ I have severe problems doing my usual activities
- ☐ I am unable to do my usual activities

Please select the ONE box that best describes your health TODAY.

PAIN / DISCOMFORT

- ☐ I have no pain or discomfort
- ☐ I have slight pain or discomfort
- ☐ I have moderate pain or discomfort
- ☐ I have severe pain or discomfort
- ☐ I have extreme pain or discomfort

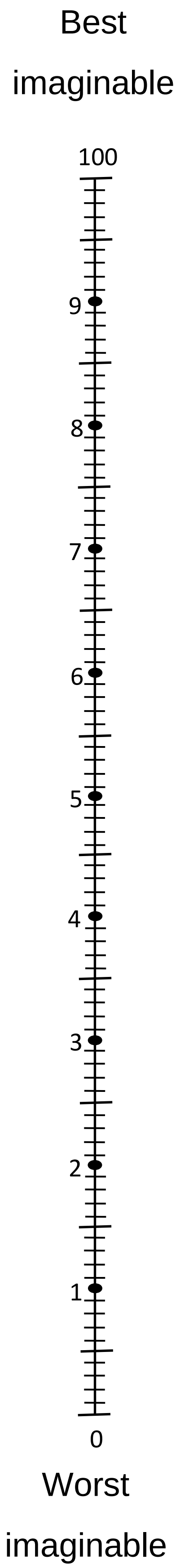
Please select the ONE box that best describes your health TODAY.

ANXIETY / DEPRESSION

- ☐ I am not anxious or depressed
- ☐ I am slightly anxious or depressed
- ☐ I am moderately anxious or depressed
- ☐ I am severely anxious or depressed
- ☐ I am extremely anxious or depressed

88. VAS

We would like to know how good or bad your health is TODAY.



This scale is numbered from 0 to 100.

100 means the best health you can imagine. 0 means the worst health you can imagine.

Please indicate on the scale how your health is TODAY.

89. 10-item Center for Epidemiologic Studies Depression Scale (CESD-10) (Andersen et al., 1994)

Below is a list of the ways you might have felt or behaved. Please indicate how often you have felt this way during the past week.

	Rarely or none of the time (less than 1 day)	**Some or a little of the time (1-2 days)**	**Occasionally or a moderate amount of time (3-4 days)**	**All of the time (5-7 days)**
I was bothered by things that usually don't bother me				
I had trouble keeping my mind on what I was doing				
I felt depressed				
I felt that everything I did was an effort				
I felt hopeful about the future				
I felt fearful				
My sleep was restless				
I was happy				
I felt lonely				
I could not "get going"				

90. Dyadic Relationship Scale (DRS) (Sebern et al. 2007)

This series of questions address some of the difficulties that people face as they care for a relative. We would like to know how helping your loved one has affected your relationship with them during the past week. How much do you agree or disagree with the following statements?

Because of helping my loved one:	**Strongly agree**	**Agree**	**Neutral**	**Disagree**	**Strongly disagree**

I felt closer to my loved one than I have in a while.					
I have learned some good things about my loved one.					
I felt angry toward my loved one.					
I felt depressed because of my relationship with my loved one.					
I felt resentful toward my loved one.					
I have had more patience than I have had in the past.					
I have learned some good things about myself.					
I felt that my relationship with my loved one was strained.					
I have learned some nice things about other people in my life.					
Communication between my loved one and me has improved.					
I felt that my loved one made requests over and above what he/she needed.					

91. Relationship Assessment Scale - 1 item (Hendrick, 1988)

	Not satisfied **1**	**2**	**3**	**4**	**Very satisfied** **5**
In general, how satisfied are you with your relationship with your loved one?					

Module 1

92. Do you feel you had a choice in taking on this responsibility of caring for your loved one?

- ☐ No
- ☐ Yes

93. Revised Familism Scale (RFS) (Losada et al., 2020)

The following questions examine family relationships. Please rate on the scale how much you agree or disagree with each statement:

	Strongly disagree	**Disagree**	**Neither agree nor disagree**	**Agree**	**Strongly agree**
1 - One should make great sacrifices in order to guarantee a good education for his/her children.					
2 - I would help within my means if a relative told me that they are in financial difficulty.					
3 - One should have the hope of living long enough to see his/her grandchildren grow up.					
4 - A person should share his/her home with uncles, aunts or first cousins if they are in need.					
5 - When someone has problems s/he can count on the help of relatives. (Generally)					
6 - When one has problems, one can count on the help of relatives. (Oneself/In relation to self)					
7 - One can count on help from his/her relatives to solve most problems.					

8 - Much of what a son or daughter does should be done to please the parents.					
9 - The family should consult close relatives (uncles, aunts) concerning its important decisions.					
10 - One should be embarrassed about the bad things done by his/her brothers or sisters.					
11 - Children should live in their parents' house until they get married.					
12 - A person should help his or her elderly parents in times of need, for example, help financially or share a house.					
13 - A person should live near his or her parents and spend time with them on a regular basis.					
14 - A person should always support members of the extender family, for example, aunts, uncles, and in-laws, if they are in need even if it is a big sacrifice.					
15 - A person should respect his or her older brothers and sisters regardless of their differences in views.					
16 - A person should be a good person for the sake of his or her family.					
17 - Children should obey their parents without question even if they believe they are wrong.					

18 - Parents and grandparents should be treated with great respect regardless of their differences in views					
19 - A person should often do activities with his or her immediate and extended families, for example, eat meals, play games, go somewhere together, or work on things together.					
20 - The family should control the behavior of children younger than 18.					
21 - A person should cherish time spent with his or her relatives.					

94. The Brief Illness Perception Questionnaire (B-IPQ) / Different format (Broadbent et al. 2006)

For the following questions, please select the number that best corresponds to your views:

How much does your loved one’s illness affect your life?

1 2 3 4 5 6 7 8 9 10

no affect at all — severely affects my life

How long do you think your loved one’s illness will continue?

1 2 3 4 5 6 7 8 9 10

a very short time — forever

How much control do you feel you have over your loved one’s illness?

1 2 3 4 5 6 7 8 9 10

absolutely no control — extreme amount of control

How much do you think your loved one’s treatment can help their illness?

1 2 3 4 5 6 7 8 9 10

not at all — extremely helpful

How much does your loved one experience symptoms from their illness?

1 2 3 4 5 6 7 8 9 10

no symptoms many severe
at all symptoms

How concerned are you about your loved one's illness?

1 2 3 4 5 6 7 8 9 10

not at all extremely
concerned concerned

How well do you feel you understand your loved one's illness?

1 2 3 4 5 6 7 8 9 10

don't understand understand
at all very clearly

How much does your loved one's illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?

1 2 3 4 5 6 7 8 9 10

not at all extremely
affected affected
emotionally emotionally

Please list in rank-order the three most important factors that you believe caused <u>your loved one's illness</u>. *The most important causes for me:*

1. _
2. _
3. __

95. Meaning in Life Questionnaire (MLQ) (Steger et al., 2006)

Please take a moment to think about what makes your life and existence feel important and significant to you. Please respond to the following statements as truthfully and accurately as you can, and also please remember that these are very subjective questions and that there are no right or wrong answers. Please answer according to the scale below:

	Absolutely untrue	**Mostly Untrue**	**Somewhat Untrue**	**Can't Say True or False**	**Somewhat True**	**Mostly True**	**Absolutely True**
I understand my life's meaning.							

I am looking for something that makes my life feel meaningful.							
I am always looking to find my life’s purpose.							
My life has a clear sense of purpose.							
I have a good sense of what makes my life meaningful.							
I have discovered a satisfying life purpose.							
I am always searching for something that makes my life feel significant.							
I am seeking a purpose or mission for my life.							
My life has no clear purpose.							

I am searching for meaning in my life.							

96. Portrait Values Questionnaire (PVQ-21) (Schwartz et al., 2001)

Here we briefly describe some people. Please read each description and think about how much each person is or is not like you.

How much is this person like you?

	very much like me	**like me**	**somewhat like me**	**a little like me**	**not like me**	**not like me at all**
It is important to him/her to be rich. He/she wants to have a lot of money and expensive things.						
He/she thinks it is important that every person in the world should be treated equally. He/she believes everyone should have equal opportunities in life.						
It's very important to him/her to show his/her abilities. He/she wants people to admire what he/she does.						
It is important to him/her to listen to people who are different from him/her. Even when he/she disagrees with them, he/she still wants to understand them.						
It's very important to him/her to help the people around him/her. He/she wants to care for their well-being.						
Being very successful is important to him/her. He/she hopes people will recognize his/her achievements.						
It is important to him/her to get respect from others. He/She wants people to do what he/she says.						

It is important to him/her to be loyal to his/her friends. He/she wants to devote himself/herself to people close to him/her.						
He/she strongly believes that people should care for nature. Looking after the environment is important to him/her.						

Module 2

Here are some questions about your loved one's living arrangements and the geographic distance between you and them. Please read each of the questions carefully and choose the answer that best applies to your loved one's situation.

Skip to question 105 if you answered "yes" to question 39

97. Over the past month, how often did you visit your loved one?

☐ Daily
☐ More than once a week
☐ Once a week
☐ Less than once a week

98. Over the past 3 months, how often did you feel unable to continue caring for your loved one because you don't live together?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always

99. Travel time to visit your loved one is:

☐ Greater than the time actually spent visiting
☐ Equal to the time spent visiting
☐ Shorter than the time spent visiting

100. To what extent is the geographic distance between you and your loved one, a barrier to your investment in their care?

☐ Not at all
☐ A little
☐ Somewhat
☐ A lot

101. Do you feel that the travel time to your loved one, negatively impacts your personal daily activities ?

For example, housework, shopping, social outings, religious activities, etc.

☐ Not at all
☐ A little
☐ Somewhat
☐ A lot

102. Since the onset of care dependency, have you ever considered moving to shorten the geographic distance between you and your loved one?

☐ No
☐ Yes

103. Do you feel that the geographic distance between you and your loved one, negatively impacts your relationship with them?

☐ Not at all
☐ A little
☐ Somewhat
☐ A lot

104. Over the past 3 months, how often did you feel like leaving the care of your loved one to someone else, due to the travel time it takes to visit them?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always

We would now like to ask you some questions relating to the mode of transportation you are using and the help that your loved one might receive from you, regarding their transportation needs.

105. What is your primary mode of transportation during a typical week?

Public transport includes: bus, coach, tram and metro

☐ Walking
☐ Bicycle
☐ Car
☐ Motorcycle
☐ Train
☐ Public transport

106. Is your loved one currently able to get to the services they are using or activities by themselves?

For example, drive or use public transportation to medical services, shopping or errands, social activities, family or personal business, religious activities, etc.

☐ No, they need assistance.
☐ Yes (Skip to question 108)

107. Please indicate the reason(s) why your loved one needs assistance to get to these services or activities:

Please select all that apply.

☐ Diagnosed Health condition/s as indicated earlier
☐ Hearing impairment
☐ Vision impairment
☐ Reduced mobility
☐ Prescription drug side effects
☐ They do not have a driver’s license
☐ Old age
☐ If Other, please specify

108. *Skip to question 108 if you answered “no” to question 106*

What is your loved one's primary mode of transportation during a typical week?

Public transport includes: bus, coach, tram and metro

☐ Walking
☐ Bicycle
☐ Car

- ☐ Motorcycle
- ☐ Train
- ☐ Public transport

109. Over the past 3 months, how much did you assist your loved one to get to the following services they are using or activities?

For example, assisting by driving them to these services/activities or helping them with using public transportation.

Not Applicable option is provided in case some of these services/activities are irrelevant to your loved one's circumstances or you don't personally assist them to get to these services/activities

	For all of their trips	**For about 75% of their trips**	**For about 75% of their trips**	**For about 75% of their trips**	**For about 75% of their trips**	**For about 75% of their trips**
Medical services						
Shopping or errands						
Social and recreational activities						
Family or personal business						
Religious activities						

110. How long does it take you to get your loved one to the following services/activities?

Not Applicable option is provided in case some of these services/activities are irrelevant to your loved one's circumstances or you don't personally assist them to get to these services/activities

	Less than 15 minutes	**Less than 15 minutes**	**Less than 15 minutes**	**Less than 15 minutes**	**Less than 15 minutes**	**Less than 15 minutes**

Medical services						
Shopping or errands						
Social and recreational activities						
Family or personal business						
Religious activities						

Skip to question 113 if you answered "Yes" to question 39

111. Is there available parking near your loved one's residence?

- ☐ No
- ☐ Yes

112. To what extent, is the availability of parking near your loved one's residence, a barrier to your investment in their care?

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A lot

113. Over the past 3 months, how often did you feel like leaving the care of your loved one to someone else, due to their transportation needs?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

114. Do you feel that the transportation needs of your loved one, negatively impact your personal daily activities?

For example, housework, shopping, social outings, religious activities etc.

- ☐ Not at all
- ☐ A little
- ☐ Somewhat
- ☐ A lot

We would now like to ask you some questions relating to the support services you, the caregiver, received in the past 6 months.

Answer questions 115 and 116 if you selected that you have received coordination services on question 74

115. You indicated that you have received coordination services providing information about the help, support and benefits that is available and how to access it. How far is your home from these services?

- ☐ Less than 15 minutes
- ☐ 15 to 30 minutes
- ☐ 30 to 60 minutes
- ☐ 60 to 90 minutes
- ☐ 90 to 120 minutes
- ☐ More than 120 minutes

116. Over the past 6 months, how often did you feel discouraged from using these coordination services due to the travel time it needs to get there?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

Answer questions 117 and 118 if you selected that you have received information services on question 73

117. You indicated that you have received services providing information about the disease that your loved one has. How far is your home from these services?

- ☐ Less than 15 minutes
- ☐ 15 to 30 minutes
- ☐ 30 to 60 minutes
- ☐ 60 to 90 minutes
- ☐ 90 to 120 minutes
- ☐ More than 120 minutes

118. Over the past 6 months, how often did you feel discouraged from using these services that provide information about the disease that your loved one has, due to the travel time it needs to get there?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

Answer questions 119 and 120 if you selected that you have received counselling services on question 74

119. You indicated that you have received counselling services. How far is your home from these services?

- ☐ Less than 15 minutes
- ☐ 15 to 30 minutes
- ☐ 30 to 60 minutes
- ☐ 60 to 90 minutes
- ☐ 90 to 120 minutes
- ☐ More than 120 minutes

120. Over the past 6 months, how often did you feel discouraged from using these counselling services due to the travel time it needs to get there?

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

Answer questions 121 and 122 if you selected that you have received self-help or support group services on question 74

121. You indicated that you have received self-help or support group services. How far is your home from these services?

- ☐ Less than 15 minutes
- ☐ 15 to 30 minutes
- ☐ 30 to 60 minutes
- ☐ 60 to 90 minutes
- ☐ 90 to 120 minutes
- ☐ More than 120 minutes

122. Over the past 6 months, how often did you feel discouraged from using these self-help or support services due to the travel time it needs to get there?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always

Answer questions 123 and 124 if you selected that you have received training services on question 74

123. You indicated that you have received training to help you develop the skills you need to provide care and cope with the burden of care. How far is your home from these services?

☐ Less than 15 minutes
☐ 15 to 30 minutes
☐ 30 to 60 minutes
☐ 60 to 90 minutes
☐ 90 to 120 minutes
☐ More than 120 minutes

124. Over the past 6 months, how often did you feel discouraged from using these training services due to the travel time it needs to get there?

☐ Never
☐ Rarely
☐ Sometimes
☐ Often
☐ Always

125. In your opinion, which service(s) would most help you as a caregiver?

Please select all that apply.

☐ Services providing information about the disease that your loved one has
☐ Coordination services providing information and advice about the type of help, support and benefits that is available to carers and how to acce
☐ Training services to help carers develop the skills they need to care and cope with the burden of care
☐ Counselling services (i.e. supportive and social counselling, etc.)
☐ Self-help or support group services
☐ If Other, please specify

126. How far would you be willing to travel for this service(s)?

☐ Less than 15 minutes
☐ 15 to 30 minutes

- ☐ 30 to 60 minutes
- ☐ 60 to 90 minutes
- ☐ 90 to 120 minutes
- ☐ More than 120 minutes
- ☐ I would prefer to receive these services online

127. Over the past 3 months, how often did you feel that you lack information about your loved one's condition?

For example, information about the course of their condition, their medical care, their medical exams results, etc.

- ☐ Never
- ☐ Rarely
- ☐ Sometimes
- ☐ Often
- ☐ Always

128. The Relationship Structures Questionnaire of the Experiences in Close Relationships - Revised (ECR-RS)

(Fraley et al., 2011)

Please read each of the following statements carefully and rate the extent to which you believe each statement best describes your feelings about your loved one.

It helps to turn to my loved one in times of need.

strongly disagree 1 2 3 4 5 6 7 strongly agree

I usually discuss my problems and concerns with my loved one.

strongly disagree 1 2 3 4 5 6 7 strongly agree

I talk things over with my loved one.

strongly disagree 1 2 3 4 5 6 7 strongly agree

I find it easy to depend on my loved one.

strongly disagree 1 2 3 4 5 6 7 strongly agree

I don't feel comfortable opening up to my loved one.

strongly disagree 1 2 3 4 5 6 7 strongly agree

I prefer not to show my loved one how I feel deep down.

strongly disagree 1 2 3 4 5 6 7 strongly agree

I often worry that my loved one doesn't really care for me.

strongly disagree 1 2 3 4 5 6 7 strongly agree

I'm afraid that my loved one may abandon me.

strongly disagree 1 2 3 4 5 6 7 strongly agree

I worry that my loved one won't care about me as much as I care about them.

strongly disagree 1 2 3 4 5 6 7 strongly agree

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129. **Big-Five Inventory Extra Short Form (BFI-2-XS)** (Soto & John, 2017)

Here are a number of characteristics that may or may not apply to you. For example, do you agree that you are someone who likes to spend time with others? Please read each of the statements carefully and rate the extent to which you agree or disagree.

I am someone who...

	Disagree strongly	**Disagree a little**	**Neutral; no opinion**	**Agree a little**	**Agree strongly**
Tends to be quiet.					
Is compassionate, has a soft heart.					
Tends to be disorganized.					
Worries a lot.					
Is fascinated by art, music, or literature.					
Is dominant, acts as a leader.					
Is sometimes rude to others.					
Has difficulty getting started on tasks.					
Tends to feel depressed, blue.					

Has little interest in abstract ideas.					
Is full of energy.					
Assumes the best about people.					
Is reliable, can always be counted on.					
Is emotionally stable, not easily upset.					
Is original, comes up with new ideas.					

130. The Pearlin Mastery Scale (Pearlin & Schooler, 1978)

On a scale of 1 to 4 with 1 meaning "Strongly Disagree" and 4 meaning "Strongly Agree", how strongly do you agree or disagree with these statements about yourself?

	Strong Disagree	**Disagree**	**Agree**	**Strongly Agree**
There is really no way I can solve some of the problems I have.				
Sometimes I feel that I’m being pushed around in life.				
I have little control over the things that happen to me.				
I can do just about anything I really set my mind to.				
I often feel helpless in dealing with the problems of life.				
What happens to me in the future				

mostly depends on me.				
There is little I can do to change many of the important things in my life.				

---

131. **Toronto Empathy Questionnaire (TEQ)** (Spreng et al., 2009)

Below is a list of statements. Please read each of the statements carefully and rate how frequently you feel or act in the manner described. There are no right or wrong answers or trick questions. Please answer each question as honestly as you can.

	Never	**Rarely**	**Sometimes**	**Often**	**Always**
When someone else is feeling excited, I tend to get excited too.					
Other people's misfortunes do not disturb me a great deal.					
It upsets me to see someone being treated disrespectfully.					
I remain unaffected when someone close to me is happy.					
I enjoy making other people feel better.					

I have tender, concerned feelings for people less fortunate than me.					
When a friend starts to talk about his\her problems, I try to steer the conversation towards something else.					
I can tell when others are sad even when they do not say anything.					
I find that I am “in tune” with other people’s moods.					
I do not feel sympathy for people who cause their own serious illnesses.					
I become irritated when someone cries.					
I am not really interested in how other people feel.					

I get a strong urge to help when I see someone who is upset.					
When I see someone being treated unfairly, I do not feel very much pity for them.					
I find it silly for people to cry out of happiness.					
When I see someone being taken advantage of, I feel kind of protective towards him/her.					

Module 3

132. **Perception of Collaboration Questionnaire (PCQ)** (Berg et al., 2008)

Here are some questions about perceptions of collaboration between you and your loved one. Please indicate the extent to which you agree or disagree with that statement

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
It is necessary for my loved one and I to work together,					

as it is harder for my loved one to solve problems and make decisions by him/herself					
My loved one makes better decisions when we work together					
My loved one and I always work together to deal with care-related decisions					
Nearly every day my loved one and I work together to make care-related decisions					
It is rare for my loved one and I to share care-related tasks and make decisions together					
My loved one enjoys the support and encouragement he/she receives when we work together					
Working together with my loved one is useful as I make up for things					

that my loved one doesn’t do well					
Solving everyday problems and making decisions together with my loved one brings us closer together					
My loved one dislikes my assistance as it makes him/her feel incompetent					

133. **Dyadic Coping Inventory (DCI) - stress communication subscale** (Bodenmann, 2000)

Please respond to any item by marking the appropriate case, which is fitting to your personal situation.

This section is about how you communicate your stress with your loved one:

	Very rarely	Rarely	Sometimes	Often	Very often
I let my loved one know that I appreciate his/her practical support, advice, or help					
I ask my loved one to do things for me when I have too much to do					
I show my loved one through my behaviour					

when I am not doing well or when I have problems					
I tell my loved one openly how I feel and that I would appreciate his/her support					

This section is about how your loved one communicates when he/she is feeling stressed:

	Very rarely	Rarely	Sometimes	Often	Very often
My loved one lets me know that he/she appreciates my practical support, advice, or help					
My loved one asks me to do things for him/her when he/she has too much to do					
My loved one shows me through his/her behaviour that he/she is not doing well or when he/she has problems					
My loved one tells me openly how he/she feels and that he/she would appreciate my support					

134. **Mutuality scale (MS)** (Archbold et al., 1990)

Now we would like you to let us know how you and your loved one feel about each other at the current time.

	Not at all	A little	Some	Quite a bit	A great deal
To what extent do the two of you see eye to eye (agree on things)?					
How close do you feel to your loved one?					
How much do you enjoy sharing past experiences with your loved one?					
How much does your loved one express feelings of appreciation for you and the things you do?					
How attached are you to your loved one?					
How much does your loved one help you?					

How much do you like to sit and talk with your loved one?					
How much love do you feel for your loved one?					
To what extent do the two of you share the same values?					
When you really need it, how much does your loved one comfort you?					
How much do the two of you laugh together?					
How much do you confide in your loved one?					
How much emotional support does your loved one give you?					
To what extent do you enjoy the time the two of you spend together?					
How often does your					

loved one express feelings of warmth toward you?					

135. The perceived partner responsiveness scale (PPRS) (Reis et al., 2018)

Please answer the following questions about your loved one.

My loved one usually:

	Not at all true		Somewhat true		Moderately true		Very true		Completely true
really listens to me									
is responsive to my needs									
sees the "real" me									
"gets the facts right" about me									
understands me									
is on the “same wavelength” with me									
knows me well									
esteems me, shortcomings and all									
values and respects the whole package that is the "real" me									
expresses liking and									

encouragement for me									
seems interested in what I am thinking and feeling									
values my abilities and opinions									

136. **Social Support List (SSL) (**Kempen & Van Eijk, 1995; Van Sonderen, 1993)

The next questions concern the help and support you provide to your loved one. Please keep your loved one in mind.

How often do you:

	Seldom or never	Now and then	Quite often	Very often
Provide attention to your loved one				
Provide support to your loved one				
Show that you appreciate your loved one				
Provide instrumental support to your loved one				
Keep your loved one company				
Provide information and advice to your loved one				

React in a distant manner to your loved one				
Do not keep your appointments with your loved one				
Make disapproving remarks to your loved one				
Blame or holding things against your loved one				
Treat your loved one unfairly				
Make unreasonable demands to your loved one				
Interfere too much with your loved one				

The next questions concern the help and support you receive from your loved one. Please keep your loved one in mind.

How often does your loved one:

	Seldom or never	Now and then	Quite often	Very often
Provide attention to you				
Provide support to you				
Show that he/she appreciates you				
Provide instrumental support to you				
Keep you company				

Provide information and advice to you				
React in a distant manner to you				
Do not keep his/her appointments with you				
Make disapproving remarks to you				
Blame or holding things against you				
Treat you unfairly				
Make unreasonable demands to you				
Interfere too much with you your loved one				

Module 4

We will now ask you questions regarding your current work status.

137. Did you reduce your working hours due to your loved one's disease/condition (e.g. to care for your loved one)?

☐ No
☐ Yes

138. Did you stop working because of caregiving?

☐ No (skip to question 140)
☐ Yes. How many hours per week did you used to work? _______hours

139. How many hours per week did you work before reducing your working hours?

________ hours per week.

Skip to question 143 if you answered “no” to question 14

Please answer the following questions in relation to the last week OR on a typical week if last week was a holiday

140. During the last week, how many hours did you miss from work due to your loved one’s disease/condition?

Include hours missed when you came in late or left work early because you e.g. accompanied your loved one to doctor appointments, visited hospitals or clinics, or helped them with dressing, grooming, eating, or take medications.

- ☐ I did not miss any hours of work during the last week due to my loved one condition.
- ☐ I missed ____hours of work last week due to my loved one condition (skip to question 142).

141. Was any of this time missed from work unpaid?

- ☐ No, all the time I missed from work was paid.
- ☐ Yes, _____ hour(s) were unpaid.

142. During the last week, how much did your loved one’s disease/condition affect your productivity while you were working?

If you were able to work as usual, choose a low number. If you were not able to work as usual (e.g. accomplished less than usual, could not concentrate or perform certain tasks as carefully as usual), choose a high number.

Could work as usual

Could not work at all

0	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**
☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

143. Do you receive financial compensation from your loved one or another family member for the care that you provide?

- ☐ No
- ☐ Yes: _____ per month.

We would now like to ask you some questions relating to the use of home care services and the decision to hire paid care workers

Skip to question 151 if you answered "no" to question 62

144. Please indicate the home care services that your loved one has received in the last month.

Please select all that apply.

- ☐ Help with personal care (e.g. dressing/undressing, washing/showering/bathing, hair care, shaving and grooming, and going to the toilet)
- ☐ Nursing care (e.g. administering medications and injections, monitoring vital signs, dressing wounds, performing medical therapies, nutrition via tubes, prevention and management of bed sores and any medical-related types of tasks)
- ☐ Help with household activities and tasks (e.g. preparing food, cleaning, washing, ironing, sewing, shopping, and gardening)
- ☐ Practical support (e.g. eating and drinking, moving inside or outside the house (including assistance with walking or using a wheelchair), visiting family or friends, accompany to healthcare visits (e.g. doctor appointments), filling prescriptions at the pharmacy, help taking medications, and taking care of financial matters (e.g. paying the bills or managing healthcare insurance)
- ☐ Sitting services (provide company and support to the dependent when a caregiver is temporarily absent)
- ☐ Home delivered meals/ Meals-on-wheels (ready-made meals provided by a municipality or a private provider)
- ☐ Telecare (e.g alarm buttons, help lines, bed monitors, video communication systems, fall and movement detectors, smartphone apps or any other technologies that assist your loved one to continue living at home)
- ☐ Other (specify below)
- ☐ None (skip to question 146)

145. In a typical week, how many hours of the following home care service(s) does your loved one receive from one or more paid care workers?

Please note that the home care services have been separated into services provided by a national care worker, and those provided by a migrant care worker(s).

To avoid overlap in the number of hours provided, if you believe that a task fits into more than one category, please select the category that you believe best fits the task.

Only fill in the rows that correspond to the selections made in question 144

Home care service	In a typical week, how many hours of this service has been provided by a **national care worker**?	*[Only complete this column if the person you provide care for receives care from a migrant care worker]* In a typical week, how many hours of this service has been provided by a **migrant care worker**?
1. Help with **personal care** (e.g. assistance with dressing/undressing, washing, combing, shaving, going to the toilet, moving around in the house, eating, drinking and administering medication and any other non-medical types of tasks).		
2. **Nursing care**. That would include administering medications and injections, monitoring vital signs, dressing wounds, performing medical therapies, nutrition via tubes, prevention and management of bed sores and any medical-related		

types of tasks.		
3. Help with **household activities and tasks** (e.g. assistance with preparing food and drinks, cleaning the house, washing, ironing and sewing clothing, shopping for groceries or odd jobs in the house or the garden and any other household chores your loved one needs support with).		
4. **Practical support** (e.g. moving around outside the house, going on outings and visiting family or friends, contacts with healthcare (accompanying your loved one for example to the general practitioner, the hospital, therapy), arranging assistance, devices and/or home modifications and organising financial and administrative matters.		

5. Sitting services (provide company and support to the dependent when a caregiver is temporarily absent)		
6. Home delivered meals/ Meals-on-wheels (i.e. ready-made meals provided by a municipality or a private provider)		
Telecare (i.e alarm buttons, help lines, bed monitors, video communication systems, fall and movement detectors, smartphone apps or any other technologies that assist your loved one to continue living at home).		

146. Why did you decide to hire a private care worker?

Please select all that apply.

☐ It gives me more time to myself/for other tasks
☐ They can provide expertise/support that I can’t
☐ I am not able to provide care
☐ To guarantee constant care
☐ To keep my same life style
☐ To safeguard my own family
☐ I live too far away/ too much travel
☐ To provide the necessary amount of care
☐ There are a lack of other alternatives
☐ So I am able to keep on working
☐ It is cheaper than other alternatives
☐ I am not willing to provide care
☐ My loved one was willing to have a cohabiting care worker
☐ If Other, please specify

Skip to question 148 if you answered “yes” to question 64 or question 69

147. Why was it decided not to hire a migrant worker?

Please select all that apply.

☐ I would not trust a migrant worker to take care of my loved one
☐ Not able to afford this service
☐ I prefer that the care worker is a national citizen
☐ My loved one refused this solution
☐ Do not know
☐ If Other, please specify

Skip to question 151 if you answered “no” or “do not know”to question 64 or question 69

148. Why was it decided to hire a migrant worker?

Please select all that apply.

☐ Economically convenient
☐ It is useful for both myself and my loved one
☐ Migrant workers provide care tasks that local staff are not able to provide (for example late night shifts/weekends).
☐ It is common practice

☐ To avoid having my loved one live in a residential facility
☐ Do not know
☐ If Other, please specify

149. Were you involved in the decision to hire a migrant worker?

☐ No
☐ Yes

150. How did your loved one access services by a migrant care worker?[8]

Please select all that apply

☐ Through recommendations from family or friends
☐ Through a care or recruitment agency
☐ Through a church or religious organization
☐ Through a government programme

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[8] Question not asked to participants in Sweden as the question was added after ethics approval in Sweden

☐ Through a non-profit organization
☐ Through social media
☐ Other, please specify:

We would now like to ask you some questions relating to the support service that you, the caregiver, received in the past 6 months

Only answer question 151 if you selected "Information about the disease that the loved one has" on question 74

151. You indicated that you have received services providing information about the disease that your loved one has.

Do you pay for this service when you utilise it?

☐ No
☐ Yes. How much do you pay for this service when you utilise it?______.

Only answer question 152 if you selected "Coordination services providing information and advice about the type of help, support and benefits that is available to carers and how to access it (e.g. information centers, case (or care) managers, advice or guidance from a physician or social worker" on question 74

152. You indicated that you have received coordination services providing information about the help, support and benefits that is available and how to access it. Do you pay for this service when you utilise it?

☐ No
☐ Yes. How much do you pay for this service when you utilise it?______.

Only answer question 153 if you selected "Training to help carers develop the skills they need to care and cope with the burden of care" on question 74

153. You indicated that you have received training to help you develop the skills you need to care. Do you pay for this service when you utilise it?

☐ No
☐ Yes. How much do you pay for this service when you utilise it?______.

*Only answer question 155 if you selected "*Counselling (i.e. supportive and social counselling, etc.)*" on question 74*

154. **You indicated that you have received counselling services. Do you pay for this service when you utilise it?**

- ☐ No
- ☐ Yes. How much do you pay for this service when you utilise it?______.

155. In this section we would like to find out about any financial costs that you may have had as a result of caring for your loved one

Please only include expenses you pay for with your own money or with household money and do not count expenses that are covered or reimbursed by a health or social insurance

- **travel to visit your loved one or to take them to appointments at hospital, hospice, GP surgery or elsewhere?**

e.g. taxis, buses, trains, planes, parking, fuel if you travel in your own car, accommodation (to be close to the hospital, hospice or elsewhere), or any other incurred travel expenses.

- ☐ No
- ☐ Yes. How much did you pay in the last month? _______

- **for childcare or care for any other dependents?**

e.g. paying someone to look after children or any other dependents while you were caring for your loved one.

- ☐ No
- ☐ Yes. How much did you pay in the last month? _______

.

- **medical care for your loved one?**

e.g. health or long-term care insurance premiums, medical consultations, physio, private ambulance, hospital admissions, prescription medicines, over the counter medications or supplements (e.g. paracetamol, vitamins, etc.), complementary or alternative medicines/therapies (i.e chiropractic and massage therapy).

- ☐ No
- ☐ Yes. How much did you pay in the last month? _______

- **your loved one's food, meals, household goods, incidentals or clothing?**

- ☐ No
- ☐ Yes. How much did you pay in the last month? _______.

- **your loved one's housing payments, rent, utilities or home maintenance and repairs?**

e.g. electricity, water, heating, phone, internet and yard care.

☐ No
☐ Yes. How much did you pay in the last month? _______

- **home care or in-home respite care services?**

*In-home respite care is temporary or short-term care of an individual that is provided at their home by someone other than the person’s normal caregiver.

☐ No
☐ Yes. How much did you pay in the last month? _______

- **out-of-home respite services for your loved one**?

e.g. day-care services and temporary stay at a residential or nursing home.

☐ No
☐ Yes. How much did you pay in the last month? _______

156. In the last month, have you had out-of-pocket expenses for any of the following aids, appliances and modifications due to your loved one’s condition?

- **walking aids (e.g. stick/crutch, walker, cane, wheelchair, scooter)?**

☐ No
☐ Yes. How much did you pay in the last month? _______

- **home living aids (e.g. lifting/reclining armchair, stair lift, bath lift, shower seat, raisers for bed)?**

☐ No
☐ Yes. How much did you pay in the last month? _______

- **home or car modifications (e.g. ramps, rails, home extensions, wheel chair lift, boot hoist)?**

☐ No
☐ Yes. How much did you pay in the last month? _______

- **personal alarms or monitoring systems (e.g. webcams, intercom and tracking systems)?**

  ☐ No
  ☐ Yes. How much did you pay in the last month? _______

- **other aids or appliances?**

For example, incontinence aids (pads, pants, waterproof sheets/chair covers), respiratory aids (e.g. home oxygen, NIV machine), posture aids (e.g. back sup

☐ No
☐ Yes. How much did you pay in the last month? _______

157. In the last month, have you incurred any costs relating to health problems of your own that have occurred as a result of your caring role e.g.

☐ No (skip to end of questionnaire)
☐ Yes. How much did you pay in the last month? _______

158. Please specify the type and amount of the cost(s) relating to health problem(s) of your own that have occurred as a result of your caring role

Nature of cost e.g. physio for back injury	Cost in in the last month
1	
2	
3	
4	
5	
6	
7	
8	

Thank you for completing our survey.

We very much appreciate the information that you have provided and your time taken in completing this survey. You can find the latest updates on our project at: https://www.entwine-icohort.eu/

If you have any further questions on the survey, please send us an email at: entwinestudy@bangor.ac.uk

D3 Appendix – Participant Information Sheet

Participant Information Sheet
for
ENTWINE-iCohort Study in Informal Caregiving

You have been identified as, or identified yourself as someone who is **currently providing informal care** to a friend or loved one who has care needs arising from a health condition or because you are **currently receiving care** from a loved one due to your own health condition.

We would like to invite you to take part in a European research study. This study is led by Bangor University (UK) in collaboration with the University Medical Center of Groningen (The Netherlands), Bar-Ilan University (Israel), Uppsala University (Sweden) and the National Institute of Health and Science on Ageing (Italy). Before you decide whether to take part, it is important for you to understand why the study is being undertaken and what it involves. Please take time to read the following information carefully and discuss it with others if you wish. If there is anything that is not clear or if you would like more information, you can contact us using the details provided below.

What is the purpose of this study?

We are carrying out this large research study across the UK, the Netherlands, Italy, Israel, Sweden, Poland, Germany, Ireland and Greece in order to identify factors that are relevant and potentially important to caregivers' and care recipients' experience. By identifying the current experience and any caregiving challenges faced by informal caregivers and care receivers in different countries with different care systems, we hope to establish who needs support, what kind, and when.

This study has five goals:

- To describe the nature and level of willingness and motivations to provide care across different countries and cultures,
- To identify factors that act as personal or geographical barriers or facilitators of caregiving,
- To explore the nature of shared experience reported by caregiver-care receiver couples/pairs,
- To identify differences across countries in the use of formal versus informal caregiving and the factors that influence this,
- To gather information about opportunities and challenges of any household-based migrant care work employed to support informal caregiving.

Do I have to take part?

Participation in this study is completely voluntary. If you decide to take part you will be asked to provide your consent in the next step on the online form you have accessed. Following consent, you are still free to withdraw at any time and without giving a reason.

What will I be asked to do if I decide to take part?

If you decide to take part, you will first complete the attached Consent Form.

You will then receive two different e-mails: one with a copy of this information letter and your consent and another one with the link to the survey to access on your smartphone, tablet or computer.

You will be asked to complete a baseline questionnaire as either a caregiver or a care recipient. Six months later you will receive a link via email inviting you to complete a follow-up questionnaire so that we can gain more information about how your situation may have changed over the last 6 months.

During the six months, we will also invite you to answer a number of short questions each week. After completing the baseline questionnaire, you will receive further instructions on how to fill in the weekly questions which can also be completed electronically on your personal device (e.g., smartphone, tablet, computer). You would receive the link by email every week for 6 months with a reminder.

If you are caring for your loved one, we would be asking for approximately sixty minutes of your time to complete the baseline and the follow-up questionnaire. Filling in the weekly questions takes about ten minutes per week.

If you receive care from your loved one, would be asking for approximately forty minutes of your time to complete the baseline and the follow-up questionnaire. Filling in the weekly questions takes about 10 minutes per week.

We would appreciate if you were able to do all parts of our study but as detailed below you have the right to complete only those questions that you wish to.

Will my taking part in this study be kept confidential?

All information collected in this study will be kept strictly confidential. Only members of the research team will have access to it. All collected data is anonymised and stored securely according to national data protection regulations. We will also follow all privacy rules in reporting of the study - no names or details that would identify specific individuals will be included. Securely stored personal data (email) will be stored for 3 years; anonymized research data will be stored for 15 years in case we need to check it and for future analyses.

You can find out more about how we use your information:

- by sending an email to our research team (entwinestudy@bangor.ac.uk)
- or by contacting Bangor University Data Protection Officer – Jenny Amphaeris (j.amphaeris@bangor.ac.uk)

In exceptional cases when information given suggests that yourself or another person is at serious risk (of severe personal distress, abuse, malpractice), the Researcher will seek your consent to share this information with the Principal Investigator and other relevant professionals as appropriate. If your consent is not given, only in these exceptional and specific circumstances does the Researcher have the right to inform the Principal Investigator and other relevant professionals. Your agreement to this is given by initialling the box on the Consent Form.

Are there any possible disadvantages, advantages or benefits if I take part?

The information you provide in this survey will help increase understanding of the challenges and experiences of informal caregivers and care recipients. The data gathered will be useful in developing evidence-based policy recommendations and for the development of new interventions to support caregiving and care receiving. Whilst there may be no direct benefits to you, there are potential long-term benefits to others.

We know of no disadvantages or risks associated with taking part in the study, other than that we ask for some of your time. In the unlikely event that the questions in the survey cause you distress at the time of taking part, please feel that you can take a break before deciding whether or not to continue or to omit some answers. You should also keep in mind your right to withdraw from the study without providing us with a reason.

If the issues addressed raise any later questions with you, you can also contact a member of your healthcare team, your GP, or if you prefer, one of the following help-lines and organizations for support and useful information:
https://www.bangor.ac.uk/studentservices/mentalhealth/support-information.php.en#tab2

Will I get any expenses or payments if I take part?

We are unable to pay people for taking part in this study.

What will happen to the results of the study?

The results will be written up for publication in scientific and care-related journals and will likely also be presented at local, national and international conferences involving a range of audiences- academic, policy and practitioner groups, caregiving or patient organisations. In this way, it is intended that our findings inform future research, policy and practice to benefit support for caregiving and care receiving. You will also be asked if you would like a copy of the study findings.

Who is organising this study?

This study is being carried out by Mikołaj Zarzycki, Eva Bei, Giulia Ferraris, Saif Elayan and Oliver Fisher as part of their PhD research within a large EU funded ENTWINE project supporting research in informal caregiving. It is supervised by Prof Val Morrison (Principal Investigator at Bangor University), Dr Noa Vilchinsky (Bar-Ilan University), Prof Mariët Hagedoorn and Prof Erik Buskens (University of Groningen, University Medical Center Groningen) and Dr Giovanni Lamura (National Institute of Health and Science on Ageing, Italy).

Who can I contact for further information?

For more information about this research, please contact:

ENTWINE-iCohort Study
Research Team Email address:
entwinestudy@bangor.ac.uk

Principal Investigator
of the Study Prof Val
Morrison
School of
Psychology Brigantia
Building
Bangor
University
Penrallt Rd, Bangor LL57 2AS

Telephone for the UK, Ireland and Poland: 01248383010

Who has reviewed the ethics of this study?

Full approvals have been obtained from: Bangor University, School of Psychology Research Ethics and Governance Committee and the NHS Research Ethics Committee, Ref Number 20/WA/0006.

What happens after the study?

If you would like to receive a summary of the findings once the study has been completed, please simply initial the relevant box on the Consent Form.

Complaints:

If you have any complaints about the way this research has been conducted, please contact:

For UK completers: Mr Huw Ellis, Manager, School of Psychology, Bangor University, Bangor, Gwynedd, LL57 2AS; email address: h.ellis@bangor.ac.uk

Thank you for taking the time to read this Information Sheet.

D4 Appendix – Participant Consent Forms

Participant Consent Form

Title of Project: ENTWINE Prospective Cohort Study in Informal Care (ENTWINE-iCohort)

Names of Researchers: Mikołaj Zarzycki, Eva Bei, Giulia Ferraris, Saif Elayan and Oliver Fisher

By signing this consent form, you agree to the following statements:

1. I confirm that I have read Participant Information Sheet for the ENTWINE iCohort Study in Informal Caregiving for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.

3. I understand that all information collected in this study will be kept strictly confidential. Only members of the research team will have access to your data which will be anonymised and stored securely. We will also follow all privacy rules in reporting the study - no identifying details of specific individuals will be included. Securely stored personal data (email) will be stored for 3 years and anonymized research data will be stored for 15 years.

☑ I have read the above information, and I agreed to take part in the above study.

Participant Consent Form for the Follow-up Survey

Title of Project: ENTWINE Prospective Cohort Study in Informal Care (ENTWINE-iCohort)

Names of Researchers: Mikołaj Zarzycki, Eva Bei, Giulia Ferraris, Saif Elayan and Oliver Fisher

By signing this consent form, you agree to the following statements:

1. I confirm that I have read Participant Information Sheet for the ENTWINE iCohort Study in Informal Caregiving for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason and without my medical care or legal rights being affected.

3. I understand that all information collected in this study will be kept strictly confidential. Only members of the research team will have access to it. Everyone involved in this study will keep your data safe and secure. We will also follow all privacy rules. No names or details that would identify specific individuals will be included in study reports. At the end of the study, we will save some of the data in case we need to check it and for future research. Securely stored personal data (email) will be stored for 3 years; anonymized research data will be stored for 15 years.

☑ I have read the above information, and I agreed to take part in the above study.

D5 Appendix – Detailed demographic data for caregivers and care recipients

Table 1 Cross-country and overall demographic data for informal caregivers

		Country of residence																		**Total**		
		Germany		**Greece**		**Ireland**		**Israel**		**Italy**		**Netherlands**		**Poland**		**Sweden**		**UK**		**N**	**% or M(SD)**	**χ^2 / F** p value
		N	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**			
Age		25	58.16 (14.27)	80	53.58 (11.48)	42	55.47 (10.49)	125	50.85 (15.97)	187	53.13 (10.91)	189	57.69 (10.42)	69	52.33 (11.95)	90	60.97 (12.65)	139	60.02 (11.49)	946	55.72 (12.49)	F=9.72 p=.000*** df=8
Gender	**Female**	18	75%	68	85%	40	95%	101	81%	161	87%	171	90%	62	90%	76	84%	122	88%	819	87%	16.65 p=.408 df=16
	Male	6	25%	12	15%	2	5%	24	19%	24	13%	17	9%	7	10%	14	16%	16	12%	122	13%	
	Other	0	0%	0	0%	0	0%	0	0%	1	1%	1	1%	0	0%	0	0%	1	1%	3	0%	
Education	**Primary**	0	0%	2	3%	2	5%	0	0%	0	0%	2	1%	0	0%	3	3%	1	1%	10	1%	258.15 p=.000*** df=32
	Secondary	2	8%	19	24%	6	14%	22	18%	15	8%	28	15%	8	12%	14	16%	14	10%	128	14%	
	Post-secondary vocational education	13	52%	15	19%	9	21%	16	13%	79	42%	134	71%	12	17%	23	26%	43	31%	344	36%	
	Post-secondary academic education	8	32%	43	54%	25	60%	87	70%	93	50%	23	12%	41	59%	47	52%	80	58%	447	47%	
	Not listed or other	2	8%	1	1%	0	0%	0	0%	0	0%	2	1%	8	12%	3	3%	1	1%	17	2%	
Employed	**No**	14	56%	31	39%	29	69%	46	37%	93	50%	97	51%	30	44%	48	53%	92	66%	480	51%	35.29 p=.000*** df=8
	Yes	11	44%	49	61%	13	31%	79	63%	94	50%	92	49%	39	56%	42	47%	47	34%	466	49%	
Other informal caregiver(s)	**No**	16	64%	38	48%	27	64%	51	41%	105	56%	130	69%	36	52%	66	73%	93	67%	562	59%	42.97 p=.000*** df=8
	Yes	9	36%	42	53%	15	36%	74	59%	82	44%	59	31%	33	48%	24	27%	46	33%	384	41%	
Provided care to other CR in the past	**No**	16	64%	46	58%	23	55%	80	64%	125	67%	74	39%	45	65%	63	70%	75	54%	547	58%	43.63 p=.000*** df=8
	Yes	9	36%	34	43%	19	45%	45	36%	62	33%	115	61%	24	35%	27	30%	64	46%	399	42%	
Help and support from services	**No**	2	100%	51	64%	30	73%	59	48%	111	59%	91	50%	51	74%	54	60%	100	73%	549	60%	34.98 p=.000*** df=8
	Yes	0	0%	29	36%	11	27%	63	52%	76	41%	92	50%	18	26%	36	40%	37	27%	362	40%	
Cash benefits	**No**	14	56%	76	95%	22	52%	117	94%	162	87%	171	90%	59	86%	87	97%	100	72%	808	85%	100.26

	Yes	11	44%	4	5%	20	48%	8	6%	25	13%	18	10%	10	14%	3	3%	39	28%	138	15%	p=.000*** df=8
Marital status	**Single**	3	12%	18	23%	5	12%	28	22%	49	26%	16	8%	13	19%	5	6%	9	6%	146	15%	79.73 p=.000*** df=32
	Married/domestic partnership	19	76%	44	55%	34	81%	82	66%	120	64%	138	73%	49	71%	68	76%	107	77%	661	70%	
	Divorced	3	12%	13	16%	2	5%	11	9%	10	5%	17	9%	5	7%	10	11%	15	11%	86	9%	
	Widowed	0	0%	4	5%	1	2%	2	2%	3	2%	5	3%	2	3%	5	6%	5	4%	27	3%	
	Other	0	0%	1	1%	0	0%	2	2%	5	3%	13	7%	0	0%	2	2%	3	2%	26	3%	
Income level[9]	**Bracket one**	17	81%	62	97%	38	90%	50	49%	117	71%	144	94%	33	55%	51	60%	101	78%	613	74%	245.51 p=.000*** df=24
	Bracket two	1	5%	1	2%	2	5%	6	6%	26	16%	7	5%	7	12%	2	2%	10	8%	62	8%	
	Bracket three	3	14%	1	2%	2	5%	9	9%	14	8%	0	0%	12	20%	2	2%	17	13%	60	7%	
	Bracket four	0	0%	0	0%	0	0%	38	37%	8	5%	3	2%	8	13%	30	35%	2	2%	89	11%	
Religion	**Religious**	14	61%	63	82%	27	64%	110	88%	NR	NR	97	52%	35	54%	NR	NR	80	59%	426	65%	58.60 p=.000*** df=6
	Non-religious	9	39%	14	18%	15	36%	15	12%	NR	NR	90	48%	30	46%	NR	NR	55	41%	228	35%	
Ethnicity	**British or Irish**	NR	NR	0	0%	42	100%	5	4%	NR	NR	NR	NR	1	1%	NR	NR	124	91%	172	38%	982.09 p=.000*** df=16
	Eastern and Central European	NR	NR	3	4%	0	0%	25	20%	NR	NR	NR	NR	68	99%	NR	NR	1	1%	97	21%	
	Mediterranean	NR	NR	76	95%	0	0%	7	6%	NR	NR	NR	NR	0	0%	NR	NR	1	1%	84	19%	
	Jewish	NR	NR	0	0%	0	0%	72	58%	NR	NR	NR	NR	0	0%	NR	NR	2	1%	74	16%	
	Other ethnic group(s)	NR	NR	1	1%	0	0%	16	13%	NR	NR	NR	NR	0	0%	NR	NR	8	6%	25	6%	
Relationship of CG to CR	**spouse/partner**	10	40%	7	9%	18	43%	19	15%	44	24%	84	44%	11	16%	55	61%	57	41%	305	32%	187.98 p=.000*** df=32
	parent/parent-in-law	11	44%	59	74%	10	24%	70	56%	106	57%	66	35%	42	61%	17	19%	52	37%	433	46%	
	daughter/son	1	4%	6	8%	11	26%	5	4%	24	13%	17	9%	2	3%	13	14%	15	11%	94	10%	
	another family member	3	12.0%	6	7.5%	2	4.8%	23	18.4%	9	4.8%	9	4.8%	9	13.0%	3	3.3%	7	5.0%	71	7.5%	
	non-relative member	0	0%	2	3%	1	2%	8	6%	4	2%	13	7%	5	7%	2	2%	8	6%	43	5%	

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[9] The income brackets provided in the questionnaire differed between the countries as they were adjusted to reflect differences in average incomes of the population and costs of living. These values were derived from the Survey of Health, Ageing and Retirement in Europe (SHARE) with exceptions for the UK, where values were derived from The English Longitudinal Study of Ageing (ELSA), and for Ireland, where the brackets were derived from The Irish Longitudinal Study on Ageing (TILDA). For example, the income brackets for the UK were as follows: 1 - less than £800; 2 - between £800 and 1500; 3 - between £1500 and £4000; 4 - more than £4000.

Caring period	**< year**	2	8%	14	18%	6	14%	22	18%	27	14%	17	9%	10	14%	10	11%	15	11%	123	13%	8.42 p=.393 df=8
	> year	23	92%	66	83%	36	86%	103	82%	160	86%	172	91%	59	86%	80	89%	124	89%	823	87%	
Sharing the same household with CR	**No**	11	44%	37	46%	6	14%	82	66%	62	33%	87	46%	29	42%	26	29%	42	30%	382	40%	63.72 p=.000*** df=8
	Yes	14	56%	43	54%	36	86%	43	34%	125	67%	102	54%	40	58%	64	71%	97	70%	564	60%	
Choice in taking on the responsibility of caring	**No**	16	64%	61	76%	34	81%	82	66%	134	72%	158	84%	46	67%	78	87%	103	74%	712	75%	26.22 p=.001** df=8
	Yes	9	36%	19	24%	8	19%	43	34%	53	28%	31	16%	23	33%	12	13%	36	26%	234	25%	
Total period of caregiving in weeks (range in years)		25	243.16 (.24-29)	80	315.53 (.01-49)	42	479.99 (.03-32)	125	243.49 (.01-30)	187	406.82 (0.8-50)	189	397.00 (.07-30)	69	298.37 (.17-43)	90	310.27 (.17-31)	139	446.83 (.05-41)	946	363.26 (.01-50)	F=3.77 p=.000*** df=8
Number of hours spent on household activities and tasks per week		25	20.28 (14.68)	80	12.71 (10.61)	42	23.65 (14.90)	125	7.75 (11.62)	187	21.88 (18.87)	189	12.42 (13.23)	69	26.10 (20.91)	90	15.67 (12.67)	139	21 (17.10)	946	16.97 (16.40)	F=16.13 p=.000*** df=8
Number of hours spent on personal care per week		25	11.64 (9.80)	80	10.39 (12.36)	42	11.66 (10.93)	125	3.75 (6.15)	187	12.54 (12.73)	189	5.92 (9.46)	69	7.90 (8.56)	90	5.87 (8.28)	139	7.98 (9.58)	946	8.17 (10.46)	F=10.71 p=.000*** df=8
Number of hours spent on practical support per week		25	15.51 (11.93)	80	11.16 (11.55)	42	18.00 (13.19)	125	6.21 (8.28)	187	13.07 (11.64)	189	9.40 (11.98)	69	15.79 (14.37)	90	9.83 (10.74)	139	12.89 (12.64)	946	11.42 (12.04)	F=7.99 p=.000*** df=8
Number of hours spent on emotional support per week		25	11.79 (9.51)	80	10.26 (10.75)	42	16.43 (17.86)	125	9.17 (15.26)	187	12.96 (15.22)	189	10.09 (14.88)	69	10.48 (10.29)	90	10.17 (14.13)	139	15.41 (17.21)	946	11.69 (14.86)	F=2.82 p=.004** df=8
Total number of hours spent on caregiving per last week		25	68.84 (47.26)	80	49.77 (44.78)	42	82.95 (54.69)	125	30.93 (39.14)	187	73.71 (70.41)	189	40.70 (41.33)	69	72.50 (56.10)	90	49.05 (44.49)	139	63.01 (48.03)	946	55.71 (53.70)	F=11.79 p < .001 df=8
CG's health condition	**A physical impairment or disability**	3	12%	6	8%	6	14%	20	16%	11	6%	30	16%	2	3%	13	14%	20	14%	111	12%	21.91[10] p=.005** df=8
	Sight or hearing loss	2	8%	1	1%	2	5%	13	10%	7	4%	15	8%	1	1%	13	14%	12	9%	66	7%	
	A mental health problem or illness	2	8%	7	9%	7	17%	14	11%	11	6%	18	10%	2	3%	7	8%	18	13%	86	9%	
	A learning disability or difficulty	0	0%	2	3%	1	2%	5	4%	3	2%	4	2%	2	3%	5	6%	1	1%	23	2%	
	A long-standing illness	7	28%	12	15%	11	26%	10	8%	22	12%	30	16%	18	26%	15	17%	26	19%	151	16%	
	Multimorbidity	6	24%	2	3%	0	0%	9	7%	23	12%	15	8%	7	10%	8	9%	6	4%	76	8%	

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[10] Caregiver health condition as recoded into a dichotomous variable (yes/no).

Other condition or disability	2	8%	7	9%	3	7%	11	9%	22	12%	28	15%	2	3%	14	16%	19	14%	108	11%
No conditions or disabilities	9	36%	53	66%	17	41%	64	51%	115	62%	91	48%	44	64%	45	50%	72	52%	510	54%

Note: CG – Caregiver; CR – Care recipient; NR – Not reported; *p < .05; **p < .01; ***p < .001

Table 2 Cross-country and overall demographic data for caregivers' care recipients

		Country of residence																		**Total**		
		Germany		**Greece**		**Ireland**		**Israel**		**Italy**		**Netherlands**		**Poland**		**Sweden**		**UK**		**N**	**% or M(SD)**	**χ^2 / F** p value
		N	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**	**N**	**% or M(SD)**			
Age of CR		25	75.64 (12.29)	80	76.27 (18.72)	42	58.92 (22.72)	125	73.97 (19.60)	187	68.51 (20.66)	189	65.99 (19.27)	69	74.69 (14.48)	90	64.72 (18.59)	139	70.00 (19.43)	946	69.45 (19.64)	F=6.17 p=.000*** df=8
KATZ (ADL) score		25	2.80 (2.04)	80	2.83 (2.30)	42	2.95 (2.09)	125	3.38 (2.40)	187	2.25 (2.17)	189	3.56 (2.08)	69	2.20 (2.20)	90	3.42 (2.27)	139	2.81 (2.13)	946	2.93 (2.27)	F=6.87 p=.000*** df=8
Gender	**Female**	11	44%	62	78%	14	33%	75	61%	107	57%	74	40%	43	63%	29	32%	56	40%	471	50%	68.09 p=.000*** df=8
	Male	14	56%	18	23%	28	67%	49	40%	80	43%	113	60%	25	37%	61	68%	83	60%	471	50%	
Number of CR's conditions	**No physical/mental condition**	0	0%	3	4%	1	2%	11	9%	7	4%	5	3%	1	1%	2	2%	4	3%	34	3%	40.98 p=.001** df=16
	Single health condition	6	24%	38	48%	19	45%	45	36%	98	52%	69	37%	22	32%	35	39%	42	30%	374	40%	
	Multimorbidity	19	76%	39	49%	22	52%	69	55%	82	44%	115	61%	46	67%	53	59%	93	67%	538	57%	
CR's health condition	**CR has mental or learning condition**	0	0%	3	4%	6	14%	4	3%	7	4%	19	10%	1	1%	15	17%	17	12%	72	8%	33.89 p=.000*** df=8
	CR has fractures	2	8%	8	10%	4	10%	11	9%	18	10%	13	7%	6	9%	8	9%	16	12%	86	9%	2.32 p=.969 df=8
	CR has rheumatic condition	8	32%	7	9%	11	26%	6	5%	14	7%	17	9%	15	22%	12	13%	32	23%	122	13%	48.18 p=.000*** df=8
	CR has a cardiological condition	7	28%	20	25%	14	33%	50	40%	46	25%	81	43%	32	46%	30	33%	56	40%	336	36%	24.97 p=.002** df=8
	CR has other condition(s)	9	36%	26	33%	13	31%	55	44%	70	37%	87	46%	26	38%	29	32%	67	48%	382	40%	13.90 p=.084 df=8
	CR has a stroke or cerebral vascular disease	4	16%	10	13%	8	19%	18	14%	23	12%	41	22%	13	19%	15	17%	26	19%	158	17%	8.28 p=.406 df=8

CR has Alzheimer's disease, dementia or any other serious memory impairment	10	40%	39	49%	8	19%	36	29%	72	39%	38	20%	25	36%	31	34%	46	33%	305	32%	31.53 p=.000*** df=8
CR has cancer	3	12%	13	16%	6	14%	14	11%	25	13%	36	19%	10	14%	16	18%	24	17%	147	16%	5.27 p=.728 df=8
CR has a chronic kidney disease	2	8%	2	3%	2	5%	7	6%	9	5%	6	3%	5	7%	4	4%	10	7%	47	5%	5.19 p=.737 df=8
CR has a chronic lung disease	2	8%	5	6%	7	17%	8	6%	13	7%	23	12%	3	4%	4	4%	19	14%	84	9%	16.07 p=.041* df=8
CR has diabetes	4	16%	13	16%	5	12%	34	27%	22	12%	29	15%	16	23%	10	11%	32	23%	165	17%	21.13 p=.007** df=8
CR has multiple sclerosis	0	0%	1	1%	1	2%	1	1%	6	3%	0	0%	5	7%	0	0%	3	2%	17	2%	20.30 p=.009** df=8
CR has Parkinson disease	4	16%	7	9%	2	5%	13	10%	18	10%	16	8%	3	4%	19	21%	6	4%	88	9%	23.72 p=.003** df=8
CR has not been diagnosed with any conditions	0	0%	3	4%	1	2%	12	10%	8	4%	7	4%	2	3%	2	2%	4	3%	39	4%	12.63 p=.125 df=8
CR has a traumatic brain injury	0	0%	0	0%	3	7%	1	1%	3	2%	7	4%	1	1%	1	1%	2	1%	18	2%	12.94 p=.114 df=8

Note: CG – Caregiver; CR – Care recipient; *p < .05; **p < .01; ***p < .001

D6 Appendix – Demographic group differences in key variables

Table 1 Gender differences in key study variables

	Country	**Israel**			**Italy**			**Netherlands**			**Total sample**		
Scale	Gender Subscale	Female N=101	Male N=24	t p value	Female N=161	Male N=24	t p value	Female N=171	Male N=17	t p value	Female N=819	Male N=122	t p value
RFS	Total score	48.86 (9.81)	48.58 (11.96)	t=.11 p=.905	42.32 (11.07)	51.33 (9.95)	t=-3.76 p=.000 **p=**.000***	39.28 (10.03)	41.94 (10.69)	t=-1.03 p=.303	42.20 (10.78)	46.19 (11.58)	t=-3.77 p=.000***
	Familial interconnectedness	32.64 (6.08)	32.29 (7.23)	t=.24 p=.807	28.64 (	33.41 (5.64)	t=-3.21 p=.002 **p=**.002**	27.81 (6.25)	27.41 (5.35)	t=.25 p=.796	28.56 (6.54)	30.11 (6.79)	t=-2.42 p=.016*
	Family support	8.16 (2.49)	8.04 (2.82)	t=.21 p=.828	6.40 (2.87)	8.66 (3.26)	t=-3.51 p=.001 **p=**.001**	5.85 (2.73)	6.58 (3.26)	t=-1.03 p=.300	6.65 (2.92)	7.58 (3.11)	t=-3.25 p=.001**
	Familial obligations	8.08 (3.09)	8.83 (2.72)	t=-1.08 p=.281	7.45 (3.00)	8.70 (3.90)	t=-1.82 p=.070	6.12 (2.57)	7.94 (3.52)	t=-2.66 p=.008 **p=**.008**	7.04 (3.01)	8.48 (3.20)	t=-4.87 p=.000***
IPQ	Illness threat	52.97 (8.62)	52.45 (7.10)	t=.27 p=.788	56.60 (9.38)	53.58 (10.19)	t=1.45 p=.148	56.71 (7.71)	56.29 (8.66)	t=.21 p=.833	56.56 (8.89)	54.59 (8.85)	t=2.28 p=.022*
MLQ	Presence of meaning	26.97 (5.22)	23.50 (6.33)	t=2.80 p=.006 **p=**.006**	23.44 (6.69)	24.04 (6.83)	t=-.40 p=.683	24.36 (5.12)	21.94 (5.69)	t=1.84 p=.067	24.09 (6.22)	22.88 (6.35)	t=2.00 p=.046*
	Search for meaning	22.66 (7.67)	21.12 (7.20)	t=.89 p=.374	19.41 (7.51)	20.50 (8.15)	t=-.65 p=.515	20.04 (6.18)	20.88 (6.44)	t=-.53 p=.595	20.21 (7.34)	20.91 (7.16)	t=-.99 p=.320
PVQ	Self-transcendence	2.12 (.74)	2.52 (.87)	t=-2.30 p=.023 **p=**.023*	2.08 (.67)	2.25 (1.04)	t=-.77 p=.445	2.22 (.59)	2.38 (.71)	t=-1.03 p=.300	2.15 (.69)	2.42 (.83)	t=-3.49 p=.001**
	Self-enhancement	3.35 (1.01)	3.72 (.92)	t=-1.66 p=.100	3.67 (1.04)	3.48 (1.12)	t=.80 p=.425	4.09 (1.00)	4.29 (.74)	t=-.78 p=.327	4.01 (1.04)	3.95 (.94)	t=.64 p=.518
MECS	EXMECS	26.64 (5.52)	26.75 (3.83)	t=-.11 p=.912	27.93 (4.88)	28.66 (5.32)	t=-.67 p=.498	26.61 (5.38)	26.70 (4.80)	t=-.06 p=.946	27.44 (5.09)	27.72 (4.62)	t=-.56 p=.570
	INMECS	24.86 (3.69)	23.00 (4.54)	t=2.11 p=.036 **p=**.036*	24.85 (4.25)	25.75 (4.05)	t=-.96 p=.336	25.09 (4.79)	24.94 (3.88)	t=.13 p=.895	24.81 (4.35)	24.53 (3.86)	t=.67 p=.499
WtC	Nursing care	3.81 (1.01)	3.75 (1.06)	t=.25 p=.799	4.44 (.72)	4.44 (.62)	t=.02 p=.981	4.21 (.98)	4.53 (.70)	t=-1.31 p=.189	4.13 (.93)	4.16 (.88)	t=-.32 p=.746
	Emotional care	4.45 (.58)	4.27 (.73)	t=1.12 p=.271	4.36 (.64)	4.51 (.54)	t=-1.09 p=.275	4.55 (.70)	4.61 (.42)	t=-.34 p=.732	4.41 (.69)	4.38 (.74)	t=.43 p=.660
	Instrumental care	4.36 (.69)	4.25 (.71)	t=.66 p=.509	4.53 (.59)	4.61 (.46)	t=-.64 p=.520	4.33 (.79)	4.66 (.41)	t=-2.81 p=.009 **p=**.009**	4.37 (.71)	4.38 (.63)	t=-.11 p=.911
	Global score	4.21 (.66)	4.09 (.73)	t=.75 p=.454	4.44 (.54)	4.47 (.44)	t=-.20 p=.838	4.37 (.73)	4.60 (.43)	t=-1.86 p=.073	4.29 (.67)	4.30 (.63)	t=-.09 p=.923
WHO-5		58.33 (22.72)	70.83 (14.75)	t=-3.31 p=.002 **p=**.002**	39.03 (22.74)	48.16 (21.28)	t=-1.85 p=.066	52.42 (23.63)	51.76 (24.30)	t=.10 p=.913	44.97 (24.16)	52.75 (24.81)	t=-3.30 p=.001**

GAINS	9.82 (6.67)	12.41 (5.98)	t=-1.74 p=.084	10.68 (6.37)	11.37 (6.48)	t=-.49 p=.621	14.18(6.16)	17.05 (6.95)	t=-1.81 p=.071	12.94 (6.75)	13.77 (6.87)	t=-1.26 p=.207
ZBI	17.30 (8.91)	14.08 (6.17)	t=2.09 p=.042 **p=**.042*	21.39 (8.79)	17.04 (8.80)	t=2.25 p=.025 **p=.**025*	18.59 (9.05)	16.29 (8.09)	t=1.00 p=.315	21.09 (9.27)	17.79 (9.32)	t=3.66 p=.000***
CES-D	9.26 (5.68)	6.91 (5.10)	t=1.85 p=.066	13.49 (6.52)	8.37 (5.53)	t=3.65 p=.000 **p=**.000***	9.82 (5.59)	9.05 (6.02)	t=.53 p=.593	11.97 (6.49)	9.42 (6.11)	t=4.08 p=.000***
EQ-5D Utility index	.89 (.11)	.92 (.07)	t=-1.46 p=.149	.71 (.25)	.72 (.28)	t=-.16 p=.867	.77 (.19)	.82 (.18)	t=-1.05 p=.291	.79 (.19)	.81 (.19)	t=-1.16 p=.244

Gender differences could not be examined in: Germany as there were only 6 male caregivers; Greece as there were only 12 male caregivers; Ireland as there were only 2 male caregivers; Poland there were only 7 male caregivers; Sweden as there were only 14 male caregivers; the UK as there were only 17 male caregivers. *p < .05; **p < .01; ***p < .001

Table 2 Educational differences in key study variables

	Country	Netherlands				Total sample			
Scale	Education Subscale	Primary/Secondary N=30	Vocational N=134	Higher N=23	F p value	Primary/Secondary N=138	Vocational N=344	Higher N=447	F p value
RFS	Total score	44.53 (9.56)	38.74 (9.93)	39.13 (9.91)	F=4.25 p=.016*	44.97 (10.67)	42.09 (11.30)	42.51 (10.65)	F=3.58 p=.028*
	Familial interconnectedness	30.06 (5.52)	27.49 (6.23)	27.47 (5.90)	F=2.25 p=.108	29.65 (6.49)	28.70 (6.72)	28.60 (6.49)	F=1.39 p=.249
	Family support	7.10 (2.59)	5.75 (2.68)	5.69 (3.05)	F=3.13 p=.046	7.34 (2.97)	6.61 (2.97)	6.69 (2.90)	F=3.21 p=.041*
	Familial obligations	7.93 (3.10)	6.02 (2.59)	5.95 (2.30)	F=6.56 p=.002**	8.10 (3.06)	7.03 (3.09)	7.12 (3.03)	F=6.60 p=.001**
IPQ	Illness threat	55.23 (7.40)	56.96 (8.11)	57.21 (6.68)	F=.64 p=.524	55.34 (8.98)	56.65 (8.89)	56.41 (8.95)	F=1.10 p=.333
MLQ	Presence of meaning	23.43 (4.84)	24.32 (5.20)	24.04 (5.98)	F=.36 p=.697	23.26 (5.65)	23.27 (5.97)	24.68 (6.54)	F=5.96 p=.003**
	Search for meaning	18.76 (6.12)	20.23 (6.25)	21.13 (6.01)	F=1.03 p=.356	20.62 (7.07)	19.68 (6.55)	20.60 (7.91)	F=1.70 p=.182
PVQ	Self-transcendence	2.29 (.76)	2.22 (.56)	2.26 (.65)	F=.162 p=.851	2.34 (0.82)	2.24 (0.70)	2.08 (0.69)	F=8.91 p=.000***
	Self-enhancement	4.25 (.99)	4.11 (1.00)	3.88 (.77)	F=.976 p=.379	4.08 (1.14)	4.08 (1.01)	3.90 (1.00)	F=3.50 p=.031*
MECS	EXMECS	27.30 (4.07)	26.19 (5.70)	28.00 (3.74)	F=1.47 p=.23	27.86 (5.25)	27.17 (5.45)	27.70 (4.52)	F=1.46 p=.232
	INMECS	26.93 (3.11)	24.88 (5.05)	23.60 (3.61)	F=3.66 p=.028*	25.40 (4.33)	24.78 (4.64)	24.62 (3.99)	F=1.75 p=.173
WtC	Nursing care	4.30 (.97)	4.22 (1.00)	4.20 (.79)	F=.09 p=.911	4.11 (0.98)	4.23 (0.89)	4.06 (0.93)	F=3.31 p=.037*
	Emotional care	4.71 (.46)	4.54 (.72)	4.41 (.65)	F=1.34 p=.264	4.43 (0.80)	4.46 (0.69)	4.36 (0.66)	F=2.04 p=.130
	Instrumental care	4.51 (.64)	4.34 (.79)	4.25 (.84)	F=.80 p=.447	4.39 (0.71)	4.42 (0.70)	4.34 (0.70)	F=1.31 p=.270
	Global score	4.51 (.61)	4.38 (.74)	4.29 (.67)	F=.69 p=.49	4.26 (0.72)	4.36 (0.66)	4.25 (0.65)	F=2.91 p=.055
WHO-5		56.93 (24.47)	52.98 (22.18)	40.52 (27.27)	F=3.60 p=.029*	47.13 (23.50)	46.19 (23.81)	45.75 (25.02)	F=.17 p=.84
GAINS		12.33 (4.88)	14.54 (6.40)	17.00 (6.28)	F=3.73 p=.026	11.52 (6.12)	13.43 (6.59)	13.30 (7.05)	F=4.33 p=.013*
ZBI		17.06 (8.26)	18.18 (8.93)	22.69 (8.86)	F=3.07 p=.049*	20.23 (9.65)	20.33 (9.29)	21.26 (9.23)	F=1.23 p=.290
CES-D		9.10 (4.54)	9.51 (5.54)	12.56 (6.77)	F=3.25 p=.041*	11.56 (6.25)	11.36 (6.16)	11.87 (6.77)	F=.61 p=.540
EQ-5D	Utility index	.80 (.19)	.78 (.18)	.72 (.22)	F=1.28 p=.278	0.79 (0.20)	0.77 (0.20)	0.81 (0.19)	F= 3.82 p= .022*

Educational differences could not be examined in: Germany as there were only 2 caregivers reporting primary and secondary education; Greece as there were only 15 caregivers reporting vocational education; Ireland as there were 8 caregivers with primary and secondary education, and 9 with vocational education; Israel as there were only 16 caregivers reporting vocational

education; Italy as there were only 15 caregivers reporting primary and secondary education; Poland as there were 8 caregivers with primary and secondary education achieved, and 12 caregivers with vocational education; Sweden as there were 17 caregivers with vocational education; the UK as there were 15 caregivers with primary and secondary education.
*p < .05; **p < .01; ***p < .001

Table 3 Employment differences in key study variables

	Country	**Greece**			**Israel**			**Italy**			**Netherlands**			**Poland**			**Sweden**			**UK**			**Total sample**		
Scale	Employed	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value
	Subscale	N=31	N=49		N=46	N=79		N=93	N=94		N=97	N=92		N=30	N=39		N=48	N=42		N=92	N=47		N=480	N=466	
RFS	Total score	45.06	40.83	t=1.67	47.58	49.51	t=-1.02	45.25	41.79	t=2.10	40.02	39.13	t=.604	46.33	43.58	t=1.09	36.35	34.95	t=.58	44.38	43.02	t=.88	43.26	42.19	t=1.49
		(12.18)	(10.16)	p=.098	(11.94)	(9.05)	p=.310	(11.15)	(11.29	p=.036	(10.80)	(9.35)	p=.546	(9.74)	(10.77)	p=.279	(12.15)	(10.15)	p=.557	(8.67)	(8.23)	p=.376	(11.27)	(10.58)	p=.134
	Familial interconnectedness	28.38	27.10	t=.87	31.93	32.94	t=-.86	30.07	28.47	t=1.58	27.78	27.85	t=-.08	30.00	28.82	t=.82	25.22	25.19	t=.02	29.22	29.06	t=.17	28.86	28.68	t=.42
		(6.65)	(6.29)	p=.387	(7.14)	(5.75)	p=.387	(6.75)	(7.04)	p=.115	(6.43)	(5.91)	p=.934	(5.85)	(5.91)	p=.412	(7.17)	(6.26)	p=.978	(5.17)	(5.33)	p=.861	(6.64)	(6.50)	p=.674
	Family support	8.09	6.44	t=.85	7.80	8.34	t=-1.03	7.20	6.22	t=2.24	6.08	5.75	t=.82	7.96	7.56	t=.55	5.06	4.54	t=.77	7.18	7.10	t=.17	6.91	6.64	t=1.39
		(2.93)	(2.93)	p=.017*	(3.10)	(2.15)	p=.303	(3.17)	(2.78)	p=.026*	(2.85)	(2.68)	p=.411	(2.87)	(3.05)	p=.579	(3.20)	(3.11)	p=.443	(2.55)	(2.22)	p=.859	(3.03)	(2.87)	p=.163
	Familial obligations	8.51	7.08	t=1.94	8.34	8.16	t=.32	7.83	7.42	t=.88	6.71	5.89	t=2.09	7.90	6.97	t=1.12	6.02	5.21	t=1.33	7.54	6.82	t=1.47	7.50	6.95	t=2.73
		(3.66)	(2.33)	p=.058	(3.15)	(2.97)	p=.746	(3.11)	(3.27)	p=.377	(2.82)	(2.55)	p=.038*	(3.18)	(3.52)	p=.264	(2.90)	(2.80)	p=.185	(2.61)	(2.85)	p=.142	(3.06)	(3.07)	p=.006**
IPQ	Illness threat	50.70	53.83	t=-1.60	54.93	51.67	t=2.14	57.40	54.95	t=1.77	57.55	55.86	t=1.49	57.83	57.76	t=.02	57.02	58.71	t=-.98	58.44	60.31	t=-1.19	56.85	55.73	t=1.93
		(8.85)	(8.21)	p=.112	(8.59)	(7.98)	p=.034*	(9.41)	(9.44)	p=.077	(7.68)	(7.87)	p=.138	(8.47)	(10.86)	p=.979	(8.96)	(7.16)	p=.330	(9.30)	(7.50)	p=.234	(8.97)	(8.78)	p=.052
MLQ	Presence of meaning	25.03	24.57	t=.38	24.23	27.50	t=-3.26	22.88	24.11	t=-1.26	23.85	24.41	t=-.73	22.93	24.20	t=-.74	22.95	24.42	t=-1.03	22.16	23.97	t=-1.53	23.21	24.69	t=-3.66
		(5.14)	(5.22)	p=.700	(5.94)	(5.04)	p=.001**	(7.02)	(6.30)	p=.207	(4.91)	(5.50)	p=.463	(7.16)	(6.92)	p=.459	(6.74)	(6.68)	p=.303	(6.73)	(6.35)	p=.128	(6.32)	(6.06)	p=.000***
	Search for meaning	22.96	5.55	t=-.38	21.60	22.81	t=-.85	20.05	19.06	t=.89	20.14	20.08	t=.06	25.26	25.58	t=-.22	18.91	17.28	t=1.03	17.98	16.97	t=.82	19.95	20.62	t=-1.40
		(5.55)	(6.10)	p=.701	(7.64)	(7.55)	p=.395	(7.70)	(7.41)	p=.372	(6.16)	(6.22)	p=.949	(5.78)	(5.88)	p=.82	(7.19)	(7.70)	p=.302	(6.82)	(6.91)	p=.412	(7.23)	(7.39)	p=.160
PVQ	Self-transcendence	1.89	2.03	t=-.98	2.08	2.26	t=-1.28	2.07	2.15	t=-.74	2.20	2.28	t=-.89	2.12	2.12	t=-.05	2.38	2.22	t=1.01	2.23	2.13	t=.74	2.17	2.19	t=-.52
		(.65)	(.64)	p=.329	(.79)	(.77)	p=.202	(.73)	(.74)	p=.460	(.64)	(.55)	p=.374	(.58)	(.68)	p=.958	(.65)	(.78)	p=.313	(.82)	(.75)	p=.456	(.73)	(.70)	p=.601
	Self-enhancement	4.10	4.03	t=.28	3.43	3.41	t=.09	3.83	3.47	t=2.34	4.22	4.00	t=1.55	4.14	4.32	t=-.89	4.38	4.48	t=-.58	4.41	4.15	t=1.64	4.12	3.87	t=3.75
		(1.10)	(1.14)	p=.775	(1.01)	(1.01)	p=.928	(1.07)	(.99)	p=.020*	(.98)	(.98)	p=.123	(.88)	(.83)	p=.376	(.86)	(.87)	p=.559	(.85)	(.95)	p=.103	(1.00)	(1.04)	p=.000***
MECS	EXMECS	29.16	27.81	t=1.38	27.28	26.30	t=1.00	28.24	27.74	t=.69	27.13	26.04	t=1.41	28.20	27.02	t=.97	29.22	28.19	t=1.05	27.53	29.10	t=-1.89	27.67	27.27	t=1.23
		(3.78)	(4.49)	p=.171	(5.67)	(4.95)	p=.315	(4.57)	(5.35)	p=.491	(4.77)	(5.80)	p=.159	(4.78)	(5.05)	p=.331	(4.00)	(5.34)	p=.296	(4.71)	(4.49)	p=.061	(4.85)	(5.21)	p=.217
	INMECS	25.61	25.28	t=.36	24.04	24.77	t=-1.00	25.27	24.68	t=.97	25.11	25.01	t=.14	23.43	23.76	t=-.26	24.18	23.47	t=.86	25.96	24.72	t=1.74	24.94	24.61	t=1.17
		(4.20)	(3.71)	p=.716	(4.47)	(3.56)	p=.319	(3.91)	(4.49)	p=.333	(4.78)	(4.64)	p=.881	(5.49)	(4.95)	p=.791	(3.69)	(4.12)	p=.391	(3.08)	(4.36)	p=.085	(4.29)	(4.26)	p=.239
WtC	Nursing care	4.47	4.22	t=1.25	3.81	3.80	t=.07	4.46	4.41	t=.53	4.27	4.20	t=.49	4.06	3.83	t=1.07	3.48	3.29	t=1.10	4.43	4.20	t=1.72	4.21	4.05	t=2.54
		(.71)	(.92)	p=.213	(1.06)	(1.00)	p=.942	(.69)	(.73)	p=.591	(.93)	(1.01)	p=.621	(.80)	(.87)	p=.285	(.75)	(.92)	p=.274	(.69)	(.83)	p=.087	(.88)	(.96)	p=.011*
	Emotional care	4.35	4.26	t=.48	4.34	4.47	t=-1.12	4.31	4.45	t=-1.59	4.55	4.56	t=-.06	4.21	3.92	t=1.55	4.34	4.24	t=.64	4.60	4.51	t=.75	4.42	4.39	t=.60
		(.64)	(.87)	p=.629	(.71)	(.54)	p=.264	(.70)	(.54)	p=.112	(.66)	(.70)	p=.949	(.69)	(.81)	p=.124	(.77)	(.77)	p=.520	(.53)	(.69)	p=.449	(.68)	(.70)	p=.546
	Instrumental care	4.60	4.43	t=1.22	4.27	4.38	t=-.79	4.59	4.48	t=1.35	4.42	4.29	t=1.13	4.23	4.23	t=-.004	3.86	3.61	t=1.84	4.65	4.50	t=1.63	4.44	4.31	t=2.76
		(.58)	(.64)	p=.226	(.78)	(.64)	p=.429	(.58)	(.57)	p=.178	(.74)	(.80)	p=.258	(.75)	(.69)	p=.997	(.59)	(.70)	p=.069	(.46)	(.61)	p=.105	(.68)	(.71)	p=.005**
	Global score	4.45	4.29	t=1.04	4.14	4.21	t=-.57	4.44	4.45	t=-.002	4.44	4.34	t=.92	4.24	3.97	t=1.73	3.89	3.70	t=1.51	4.54	4.41	t=1.57	4.34	4.24	t=2.39
		(.51)	(.75)	p=.300	(.75)	(.62)	p=.563	(.55)	(.50)	p=.998	(.70)	(.72)	p=.354	(.60)	(.66)	p=.088	(.54)	(.68)	p=.133	(.45)	(.53)	p=.119	(.65)	(.68)	p=.016*
WHO-5		42.70	46.12	t=-.62	54.52	64.35	t=-2.46	38.66	42.04	t=-1.01	52.32	52.39	t=-.01	23.06	36.61	t=-2.78	47.91	39.23	t=1.74	42.08	44.25	t=-.51	44.50	47.56	t=-1.93
		(26.33)	(22.24)	p=.536	(21.89)	(21.26)	p=.015*	(22.71)	(22.70)	p=.311	(24.51)	(22.65)	p=.986	(15.21)	(24.95)	p=.007**	(25.19)	(21.62)	p=.085	(23.83)	(22.71)	p=.607	(24.51)	(24.02)	p=.053
GAINS		11.61	10.02	t=1.04	10.65	10.12	t=.42	9.32	12.29	t=-3.27	14.19	14.69	t=-.54	11.10	12.00	t=-.60	16.70	13.73	t=2.36	16.43	16.68	t=-.20	13.24	12.87	t=.85
		(7.35)	(6.18)	p=.301	(6.75)	(6.55)	p=.670	(5.73)	(6.66)	p=.001**	(5.77)	(6.74)	p=.584	(6.24)	(6.09)	p=.550	(6.85)	(5.00)	p=.020*	(6.39)	(6.98)	p=.836	(6.75)	(6.77)	p=.395
ZBI		22.70	21.95	t=.34	18.95	15.36	t=2.14	21.12	20.42	t=.54	18.29	18.57	t=-.21	23.86	22.10	t=.79	22.39	25.61	t=-1.61	22.16	23.19	t=-.62	20.91	20.41	t=.82
		(10.23)	(9.15)	p=.734	(9.83)	(7.41)	p=.035*	(8.69)	(9.09)	p=.590	(9.53)	(8.39)	p=.833	(8.76)	(9.43)	p=.430	(9.06)	(9.84)	p=.110	(9.40)	(8.77)	p=.534	(9.35)	(9.28)	p=.409
CES-D		13.96	10.97	t=2.09	10.41	7.88	t=2.46	13.15	12.39	t=.78	9.55	10.03	t=-.58	15.53	12.66	t=1.58	11.39	13.80	t=-1.87	12.85	12.12	t=.60	12.02	11.25	t=1.82
		(6.48)	(6.05)	p=.040*	(5.85)	(5.31)	p=.015*	(6.91)	(6.34)	p=.436	(5.19)	(6.06)	p=.562	(6.70)	(7.93)	p=.117	(6.59)	(5.46)	p=.064	(6.83)	(6.67)	p=.549	(6.50)	(6.45)	p=.068
EQ-5D	Utility index	.77	.83	t=-1.59	.87	.91	t=-1.73	.67	.75	t=-2.16	.76	.79	t=-.79	.79	.87	t=-2.23	.83	.83	t=-.006	.78	.84	t=-	.76	.82	t=-4.61
		(.16)	(.16)	p=.116	(.11)	(.10)	p=.085	(.29)	(.20)	p=.032*	(.21)	(.16)	p=.428	(.18)	(.13)	p=.030*	(.13)	(.12)	p=.996	(.19)	(.10)	2.629	(.22)	(.16)	p=.000***
																						p=.010*			

The differences in the employment status could not be examined in: Germany as there were 11 caregivers who declared being employed; Ireland as there were 13 caregivers who declared being employed. *p < .05; **p < .01; ***p < .001

Table 4 The effects of having support from other informal caregivers on key study variables

	Country	**Greece**			**Israel**			**Italy**			**Netherlands**			**Poland**			**Sweden**			**UK**			**Total sample**		
Scale	Other carers	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value
		N=38	N=42		N=51	N=74		N=105	N=82		N=130	N=59		N=36	N=33		N=66	N=24		N=93	N=46		N=562	N=384	
	Subscale																								
RFS	Total score	42.44	42.50	t=-.02	48.01	49.35	t=-.71	43.70	43.28	t=.25	39.91	38.86	t=.66	45.33	44.18	t=.45	35.43	36.41	t=-.36	45.13	41.45	t=2.44	42.47	43.13	t=-.90
		(10.96)	(11.37)	p=.983	(9.94)	(10.42)	p=.476	(12.00)	(10.46)	p=.800	(10.19)	(9.95)	p=.509	(9.60)	(11.23)	p=.648	(11.07)	(11.82)	p=.717	(7.72)	(9.56)	p=.016*	(10.87)	(11.08)	p=.364
	Familial interconnectedness	27.50	27.69	t=-.13	32.58	32.56	t=.018	29.36	29.15	t=.19	27.87	27.69	t=.18	29.08	29.60	t=-.36	24.98	25.83	t=-.52	29.59	28.32	t=1.35	28.58	29.06	t=-1.10
		(6.60)	(6.34)	p=.896	(6.02)	(6.51)	p=.986	(7.16)	(6.65)	p=.843	(6.33)	(5.83)	p=.852	(5.13)	(6.65)	p=.715	(6.70)	(6.88)	p=.599	(4.85)	(5.83)	p=.179	(6.56)	(6.60)	p=.268
	Family support	6.97	7.19	t=-.31	7.66	8.47	t=-1.75	6.74	6.67	t=.162	5.83	6.11	t=-.66	7.88	7.57	t=.43	4.78	4.91	t=-.17	7.48	6.50	t=2.10	6.65	6.95	t=-1.54
		(3.22)	(2.86)	p=.751	(2.89)	(2.24)	p=.082	(3.18)	(2.81)	p=.872	(2.84)	(2.62)	p=.510	(2.88)	(3.07)	p=.664	(3.22)	(3.02)	p=.865	(2.21)	(2.75)	p=.038*	(3.02)	(2.86)	p=.122
	Familial obligations	7.65	7.61	t=.05	7.84	8.50	t=-1.19	7.52	7.76	t=-.51	6.56	5.74	t=1.94	8.00	6.69	t=1.61	5.66	5.58	t=.12	7.64	6.60	t=2.15	7.20	7.28	t=-.43
		(2.91)	(3.08)	p=.954	(2.93)	(3.08)	p=.235	(3.31)	(3.04)	p=.604	(2.78)	(2.49)	p=.054	(3.40)	(3.29)	p=.111	(2.75)	(3.24)	p=.904	(2.54)	(2.91)	p=.033*	(3.00)	(3.19)	p=.667
IPQ	Illness threat	51.78	53.38	t=-.82	52.19	53.33	t=-.75	56.40	55.89	t=.36	57.19	55.72	t=1.19	59.11	56.36	t=1.16	56.63	61.04	t=-2.31	59.05	59.13	t=-.04	56.48	56.04	t=.74
		(8.95)	(8.21)	p=.410	(8.30)	(8.37)	p=.454	(9.14)	(9.95)	p=.716	(7.58)	(8.25)	p=.233	(10.12)	(9.43)	p=.249	(8.16)	(7.44)	p=.023*	(8.82)	(8.69)	p=.961	(8.79)	(9.06)	p=.454
MLQ	Presence of meaning	25.26	24.28	t=.84	25.78	26.66	t=-.86	22.88	24.29	t=-1.43	23.80	24.83	t=-1.25	24.25	23.00	t=.73	24.04	22.54	t=.93	21.76	24.82	t=-2.61	23.56	24.50	t=-2.28
		(5.17)	(5.17)	p=.402	(5.66)	(5.55)	p=.391	(6.55)	(6.80)	p=.154	(5.33)	(4.86)	p=.212	(6.34)	(7.70)	p=.463	(6.56)	(7.15)	p=.351	(6.70)	(6.07)	p=.010*	(6.26)	(6.18)	p=.023*
	Search for meaning	23.26	23.30	t=-.03	21.37	23.05	t=-1.22	19.87	19.14	t=.65	19.63	21.18	t=-1.61	25.13	25.78	t=-.46	18.13	18.20	t=-.04	18.16	16.60	t=1.26	19.87	20.88	t=-2.09
		(6.57)	(5.22)	p=.972	(8.08)	(7.18)	p=.224	(7.62)	(7.49)	p=.514	(6.05)	(6.36)	p=.109	(5.29)	(6.37)	p=.646	(7.66)	(6.94)	p=.968	(6.56)	(7.33)	p=.209	(7.26)	(7.37)	p=.036*
PVQ	Self-transcendence	1.82	2.12	t=-2.13	2.25	2.16	t=.64	2.15	2.05	t=.93	2.25	2.20	t=.54	2.08	2.16	t=-.48	2.36	2.16	t=1.14	2.31	1.97	t=2.37	2.21	2.14	t=1.47
		(.62)	(.64)	p=.036*	(.87)	(.71)	p=.518	(.79)	(.65)	p=.350	(.60)	(.59)	p=.588	(.57)	(.70)	p=.631	(.72)	(.70)	p=.254	(.83)	(.66)	p=.019*	(.75)	(.67)	p=.140
	Self-enhancement	4.36	3.78	t=2.35	3.65	3.26	t=2.12	3.75	3.53	t=1.40	4.16	4.00	t=1.02	4.22	4.26	t=-.17	4.41	4.46	t=-.25	4.38	4.21	t=1.07	4.13	3.81	t=4.69
		(.96)	(1.19)	p=.021*	(1.13)	(.88)	p=.035*	(1.09)	(.97)	p=.161	(.98)	(.98)	p=.305	(.92)	(.78)	p=.863	(.87)	(.86)	p=.803	(.84)	(.97)	p=.285	(1.01)	(1.02)	p=.000***
MECS	EXMECS	27.81	28.80	t=-1.04	26.37	26.86	t=-.51	28.11	27.84	t=.37	26.86	26.03	t=.99	27.94	27.09	t=.86	28.69	28.87	t=-.15	28.08	28.02	t=.076	27.55	27.36	t=.57
		(4.20)	(4.31)	p=.301	(5.44)	(5.10)	p=.607	(5.05)	(4.89)	p=.711	(5.38)	(5.16)	p=.323	(5.63)	(4.08)	p=.477	(4.70)	(4.70)	p=.874	(4.97)	(4.09)	p=.940	(5.17)	(4.83)	p=.567
	INMECS	25.26	25.54	t=-.32	25.31	23.94	t=1.93	25.16	24.74	t=.67	25.80	23.44	t=3.27	23.69	23.54	t=.11	24.28	22.66	t=1.76	25.75	25.13	t=.95	25.21	24.14	t=3.80
		(3.59)	(4.17)	p=.746	(4.05)	(3.75)	p=.055	(4.35)	(4.05)	p=.503	(4.80)	(4.05)	p=.001**	(4.99)	(5.41)	p=.906	(3.76)	(4.09)	p=.081	(3.47)	(3.83)	p=.339	(4.26)	(4.23)	p=.000***
WtC	Nursing care	4.38	4.25	t=.68	3.93	3.71	t=1.20	4.40	4.49	t=-.82	4.35	3.97	t=2.37	4.00	3.85	t=.72	3.51	3.06	t=2.32	4.46	4.15	t=2.11	4.22	4.00	t=3.61
		(.72)	(.95)	p=.499	(1.10)	(.95)	p=.229	(.75)	(.65)	p=.411	(.88)	(1.09)	p=.020*	(.82)	(.87)	p=.473	(.83)	(.76)	p=.023*	(.65)	(.88)	p=.038*	(.88)	(.97)	p=.000***
	Emotional care	4.45	4.15	t=1.68	4.53	4.35	t=1.63	4.36	4.41	t=-.56	4.62	4.42	t=1.64	3.95	4.14	t=-1.05	4.34	4.17	t=.90	4.58	4.54	t=.40	4.45	4.34	t=2.43
		(.56)	(.93)	p=.095	(.50)	(.66)	p=.105	(.61)	(.66)	p=.572	(.61)	(.80)	p=.105	(.83)	(.70)	p=.298	(.70)	(.92)	p=.369	(.56)	(.64)	p=.685	(.65)	(.75)	p=.015*
	Instrumental care	4.55	4.44	t=.79	4.40	4.29	t=.88	4.60	4.46	t=1.59	4.51	4.03	t=3.72	4.26	4.19	t=.36	3.75	3.74	t=.06	4.68	4.44	t=2.47	4.45	4.27	t=3.72
		(.47)	(.73)	p=.432	(.70)	(.69)	p=.377	(.56)	(.60)	p=.112	(.68)	(.85)	p=.000***	(.64)	(.80)	p=.713	(.64)	(.71)	p=.950	(.47)	(.58)	p=.016*	(.66)	(.74)	p=.000***
	Global score	4.43	4.28	t=.97	4.29	4.12	t=1.42	4.43	4.47	t=-.48	4.49	4.17	t=2.68	4.12	4.05	t=.47	3.86	3.65	t=1.38	4.56	4.37	t=2.10	4.35	4.20	t=3.43
		(.47)	(.81)	p=.333	(.69)	(.65)	p=.158	(.55)	(.50)	p=.629	(.63)	(.82)	p=.009**	(.61)	(.69)	p=.636	(.59)	(.66)	p=.170	(.45)	(.53)	p=.037*	(.63)	(.71)	p=.001*
WHO-5		49.68	40.38	t=1.76	57.41	63.02	t=-1.41	39.58	41.36	t=-.53	51.96	53.22	t=-.33	28.88	32.72	t=-.71	46.96	35.33	t=2.08	41.33	45.82	t=-1.06	45.71	46.44	t=-.45
		(25.78)	(21.21)	p=.081	(22.58)	(21.32)	p=.160	(22.71)	(22.81)	p=.595	(23.36)	(24.18)	p=.736	(21.99)	(22.57)	p=.477	(24.21)	(21.05)	p=.040*	(23.16)	(23.83)	p=.288	(24.16)	(24.60)	p=.650
GAINS		10.44	10.80	t=-.24	10.09	10.47	t=-.31	10.71	10.95	t=-.25	13.51	16.47	t=-3.08	11.19	12.06	t=-.58	15.36	15.20	t=.10	16.68	16.17	t=.43	13.09	13.01	t=.17
		(6.56)	(6.82)	p=.810	(5.89)	(7.08)	p=.757	(6.29)	(6.51)	p=.802	(6.13)	(6.08)	p=.002**	(5.51)	(6.80)	p=.562	(6.44)	(5.63)	p=.917	(6.63)	(6.52)	p=.666	(6.64)	(6.96)	p=.864
ZBI		20.81	23.54	t=-1.28	16.47	16.83	t=-.23	20.68	20.89	t=-.15	17.86	19.67	t=-1.28	25.19	20.33	t=2.27	22.43	27.91	t=-2.48	22.78	21.95	t=.49	20.50	20.90	t=-.64
		(9.07)	(9.85)	p=.202	(8.60)	(8.53)	p=.814	(8.91)	(8.90)	p=.876	(8.99)	(8.87)	p=.200	(8.87)	(8.84)	p=.026*	(9.39)	(8.85)	p=.015*	(9.31)	(8.97)	p=.618	(9.34)	(9.31)	p=.522
CES-D		10.89	13.26	t=-1.68	10.21	7.85	t=2.34	13.30	12.08	t=1.25	9.82	9.71	t=.12	14.55	13.21	t=.74	11.87	14.29	t=-1.65	12.67	12.47	t=.16	11.75	11.47	t=.65
		(5.81)	(6.67)	p=.096	(5.46)	(5.58)	p=.021*	(6.67)	(6.53)	p=.213	(5.34)	(6.24)	p=.900	(6.97)	(8.10)	p=.462	(6.22)	(5.80)	p=.102	(6.57)	(7.20)	p=.871	(6.26)	(6.81)	p=.512
EQ-5D	Utility index	.81	.81	t=.09	.87	.90	t=-1.48	.71	.71	t=-.03	.78	.76	t=.79	.81	.86	t=-1.13	.83	.83	t=.13	.77	.85	t=-2.41	.79	.80	t=-1.02
		(.15)	(.17)	p=.929	(.12)	(.10)	p=.140	(.24)	(.27)	p=.973	(.18)	(.20)	p=.430	(.16)	(.15)	p=.259	(.13)	(.12)	p=.893	(.18)	(.11)	p=.017*	(.19)	(.20)	p=.304

The differences in having support from other caregivers could not be examined in: Germany as there were 9 caregivers who declared receiving support from other caregivers; Ireland as there were 15 caregivers who declared receiving support from other caregivers. *p < .05; **p < .01; ***p < .001

Table 5 The effect of caregiver's own health condition (reporting or not own health condition) on key study variables

	Country	Greece			Israel			Italy			Netherlands			Poland			Sweden			UK			Total sample		
Scale	CG's health condition	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value
		N=53	N=27		N=64	N=61		N=115	N=72		N=91	N=98		N=44	N=25		N=45	N=45		N=72	N=67		N=510	N=436	
	Subscale																								
RFS	Total score	42.20 (11.76)	43.00 (9.88)	t=-.30 p=.765	49.15 (9.56)	48.44 (10.91)	t=.38 p=.698	43.61 (10.50)	43.36 (12.60)	t=.15 p=.881	39.38 (8.51)	39.77 (11.43)	t=-.26 p=.789	45.34 (10.77)	43.80 (9.70)	t=.59 p=.556	34.64 (10.64)	36.75 (11.79)	t=-.89 p=.375	42.79 (7.65)	45.13 (9.26)	t=-1.62 p=.106	42.73 (10.41)	42.74 (11.57)	t=-.00 p=.996
	Familial interconnectedness	27.58 (7.06)	27.62 (5.06)	t=-.02 p=.977	32.98 (5.82)	32.14 (6.76)	t=.74 p=.460	29.20 (6.39)	29.38 (7.74)	t=-.18 p=.857	27.91 (5.68)	27.73 (6.61)	t=.19 p=.844	29.63 (5.96)	28.80 (5.78)	t=.56 p=.573	24.86 (6.09)	25.55 (7.35)	t=-.48 p=.630	28.77 (4.60)	29.59 (5.79)	t=-.92 p=.356	28.87 (6.22)	28.65 (6.98)	t=.51 p=.605
	Family support	7.01 (3.00)	7.22 (3.10)	t=-.28 p=.778	8.25 (2.39)	8.03 (2.72)	t=.47 p=.636	6.59 (2.96)	6.90 (3.11)	t=-.68 p=.493	5.69 (2.44)	6.13 (3.04)	t=-1.10 p=.273	7.88 (2.99)	7.48 (2.93)	t=.54 p=.587	4.06 (3.06)	5.57 (3.10)	t=-2.32 p=.022*	6.86 (2.06)	7.47 (2.77)	t=-1.47 p=.142	6.65 (2.89)	6.92 (3.03)	t=-1.42 p=.154
	Familial obligations	7.56 (2.92)	7.77 (3.15)	t=-.29 p=.766	8.28 (2.91)	8.18 (3.16)	t=.18 p=.853	7.56 (3.17)	7.73 (3.23)	t=-.35 p=.723	6.12 (2.30)	6.48 (3.05)	t=-.94 p=.348	7.65 (3.58)	6.88 (3.01)	t=.91 p=.363	5.66 (2.95)	5.62 (2.82)	t=.07 p=.942	6.83 (2.81)	7.80 (2.51)	t=.142 p=.033*	7.19 (3.05)	7.29 (3.11)	t=-.50 p=.615
IPQ	Illness threat	51.75 (8.64)	54.33 (8.27)	t=-1.28 p=.204	52.89 (8.55)	52.85 (8.16)	t=.02 p=.980	55.44 (10.35)	57.34 (7.82)	t=-1.42 p=.156	56.15 (8.09)	57.27 (7.52)	t=-.98 p=.325	58.50 (9.06)	56.56 (11.12)	t=.78 p=.435	58.20 (7.73)	57.42 (8.65)	t=.44 p=.654	59.27 (8.50)	58.86 (9.07)	t=.27 p=.783	55.98 (9.17)	56.68 (8.57)	t=-1.20 p=.229
MLQ	Presence of meaning	25.18 (4.99)	23.88 (5.47)	t=1.06 p=.290	26.21 (5.64)	26.39 (5.58)	t=-.17 p=.862	23.26 (6.26)	23.87 (7.32)	t=-.60 p=.548	24.34 (5.11)	23.92 (5.31)	t=.54 p=.588	24.31 (6.27)	22.48 (8.14)	t=1.04 p=.298	24.53 (5.94)	22.75 (7.37)	t=1.25 p=.211	23.90 (6.21)	21.56 (6.91)	t=2.09 p=.038*	24.34 (5.86)	23.47 (6.64)	t=2.13 p=.033*
	Search for meaning	22.43 (6.20)	24.96 (4.80)	t=-1.85 p=.068	21.37 (7.63)	23.40 (7.44)	t=-1.50 p=.134	19.15 (7.63)	20.19 (7.44)	t=-.91 p=.362	20.28 (6.28)	19.95 (6.10)	t=.36 p=.718	25.45 (5.82)	25.44 (5.88)	t=.01 p=.992	18.37 (7.38)	17.93 (7.57)	t=.28 p=.779	16.38 (6.42)	19.00 (7.06)	t=-2.28 p=.024*	19.88 (7.41)	20.75 (7.19)	t=-1.82 p=.069
PVQ	Self-transcendence	2.04 (.70)	1.84 (.51)	t=1.34 p=.184	2.20 (.80)	2.20 (.76)	t=.000 p=1.000	2.12 (.70)	2.09 (.79)	t=.31 p=.751	2.26 (.57)	2.22 (.63)	t=.46 p=.640	2.20 (.64)	1.98 (.61)	t=1.38 p=.170	2.27 (.69)	2.35 (.75)	t=-.52 p=.602	2.27 (.80)	2.12 (.78)	t=1.10 p=.271	2.19 (.71)	2.17 (.73)	t=.61 p=.539
	Self-enhancement	4.23 (1.01)	3.72 (1.26)	t=1.95 p=.055	3.60 (.99)	3.23 (.99)	t=2.08 p=.039*	3.63 (1.06)	3.69 (1.02)	t=-.40 p=.685	4.07 (.97)	4.15 (.99)	t=-.56 p=.571	4.21 (.93)	4.31 (.71)	t=-.46 p=.645	4.23 (.91)	4.62 (.77)	t=-2.20 p=.030*	4.38 (.86)	4.26 (.92)	t=.79 p=.429	4.00 (1.01)	3.99 (1.05)	t=.13 p=.894
MECS	EXMECS	27.94 (4.50)	29.11 (3.69)	t=-1.16 p=.249	25.73 (5.44)	27.63 (4.84)	t=-2.06 p=.041*	27.19 (4.79)	29.27 (5.01)	t=-2.84 p=.005**	26.26 (5.56)	26.91 (5.08)	t=-.84 p=.399	27.36 (4.62)	27.84 (5.53)	t=-.38 p=.703	29.13 (4.09)	28.35 (5.21)	t=.78 p=.434	27.62 (4.77)	28.53 (4.57)	t=-1.14 p=.253	27.09 (5.03)	27.92 (5.01)	t=-2.52 p=.012*
	INMECS	25.11 (3.97)	26.00 (3.72)	t=-.96 p=.338	24.51 (4.11)	24.49 (3.74)	t=.03 p=.973	24.30 (4.07)	26.05 (4.24)	t=-2.81 p=.005**	25.07 (4.94)	25.05 (4.49)	t=.03 p=.970	23.72 (4.84)	23.44 (5.76)	t=.22 p=.826	23.62 (3.75)	24.08 (4.06)	t=-.56 p=.573	25.02 (3.94)	26.10 (3.11)	t=-1.77 p=.078	24.54 (4.26)	25.06 (4.30)	t=-1.87 p=.061
WtC	Nursing care	4.32 (.90)	4.32 (.75)	t=-.007 p=.994	3.94 (.97)	3.65 (1.05)	t=1.58 p=.116	4.37 (.71)	4.55 (.69)	t=-1.72 p=.087	4.15 (1.07)	4.31 (.85)	t=-1.12 p=.263	3.87 (.88)	4.04 (.78)	t=-.83 p=.407	3.29 (.89)	3.49 (.77)	t=-1.12 p=.266	4.32 (.81)	4.38 (.67)	t=-.47 p=.636	4.11 (.95)	4.15 (.90)	t=-.63 p=.524
	Emotional care	4.26 (.88)	4.35 (.58)	t=-.43 p=.664	4.54 (.50)	4.29 (.68)	t=2.34 p=.021*	4.32 (.65)	4.47 (.59)	t=-1.59 p=.113	4.51 (.75)	4.60 (.60)	t=-.88 p=.378	3.95 (.81)	4.20 (.68)	t=-1.24 p=.217	4.25 (.77)	4.34 (.76)	t=-.53 p=.596	4.55 (.58)	4.59 (.60)	t=-.46 p=.642	4.37 (.72)	4.44 (.66)	t=-1.50 p=.133
	Instrumental care	4.52 (.66)	4.44 (.53)	t=.53 p=.598	4.42 (.66)	4.25 (.72)	t=1.40 p=.164	4.48 (.62)	4.63 (.48)	t=-1.82 p=.069	4.30 (.82)	4.41 (.72)	t=-.95 p=.342	4.17 (.73)	4.32 (.69)	t=-.78 p=.438	3.72 (.63)	3.77 (.68)	t=-.31 p=.750	4.60 (.54)	4.60 (.49)	t=-.05 p=.957	4.37 (.71)	4.39 (.69)	t=-.41 p=.676
	Global score	4.34 (.73)	4.37 (.53)	t=-.16 p=.867	4.30 (.60)	4.06 (.72)	t=2.01 p=.046*	4.40 (.52)	4.52 (.53)	t=-1.52 p=.130	4.32 (.78)	4.46 (.63)	t=-1.40 p=.162	4.03 (.67)	4.20 (.61)	t=-1.03 p=.306	3.75 (.62)	3.85 (.61)	t=-.75 p=.451	4.48 (.50)	4.51 (.46)	t=-.29 p=.767	4.28 (.67)	4.31 (.66)	t=-.64 p=.521
WHO-5		46.56 (25.37)	41.33 (20.39)	t=.92 p=.356	63.62 (21.43)	57.70 (22.21)	t=1.51 p=.132	41.60 (23.61)	38.38 (21.20)	t=.94 p=.348	54.37 (23.13)	50.48 (23.92)	t=1.13 p=.259	33.45 (23.46)	25.92 (19.25)	t=1.36 p=.177	48.00 (23.47)	39.73 (23.79)	t=1.65 p=.101	49.88 (21.89)	35.22 (22.71)	t=3.87 p=.000***	48.60 (24.45)	42.98 (23.86)	t=3.56 p=.000***
GAINS		9.98 (6.41)	11.92 (7.07)	t=-1.23 p=.219	10.17 (6.05)	10.47 (7.18)	t=-.25 p=.799	10.18 (5.94)	11.83 (6.93)	T=-1.67 p=.097	14.18 (6.23)	14.67 (6.29)	t=-.53 p=.594	11.93 (6.37)	11.04 (5.76)	t=.57 p=.565	15.15 (6.34)	15.48 (6.13)	t=-.25 p=.801	16.51 (6.36)	16.52 (6.84)	t=-.008 p=.994	12.60 (6.62)	13.59 (6.91)	t=-2.26 p=.024*
ZBI		21.77 (10.19)	23.18 (8.18)	t=-.62 p=.534	15.26 (7.25)	18.18 (9.51)	t=-1.93 p=.056	20.31 (9.26)	21.51 (8.25)	t=-.89 p=.370	18.39 (8.25)	18.46 (9.64)	t=-.05 p=.955	23.04 (8.58)	22.56 (10.19)	t=.21 p=.834	24.15 (9.03)	23.64 (10.08)	t=.25 p=.801	21.16 (8.91)	23.95 (9.29)	t=-1.80 p=.073	20.23 (9.09)	21.17 (9.57)	t=-1.54 p=.123
CES-D		11.09 (5.58)	14.18 (7.33)	t=-2.10 p=.039*	8.09 (5.37)	9.57 (5.83)	t=-1.47 p=.143	12.30 (6.91)	13.51 (6.10)	t=-1.21 p=.226	9.27 (5.30)	10.26 (5.89)	t=-1.21 p=.227	12.09 (6.78)	17.12 (7.77)	t=-2.80 p=.007**	11.20 (5.63)	13.84 (6.47)	t=-2.06 p=.042*	10.75 (5.97)	14.61 (7.03)	t=-3.49 p=.001**	10.67 (6.11)	12.77 (6.73)	t=-4.99 p=.000***
EQ-5D	Utility index	.81 (.17)	.82 (.15)	t=-.44 p=.655	.93 (.08)	.86 (.12)	t=3.64 p=.000***	.75 (.23)	.66 (.26)	t=2.38 p=.018*	.84 (.14)	.72 (.21)	t=4.34 p=.000***	.88 (.12)	.76 (.19)	t=2.89 p=.007**	.89 (.07)	.77 (.14)	t=4.71 p=.000***	.87 (.09)	.72 (.19)	t=5.89 p=.000***	.84 (.17)	.74 (.21)	t=7.59 p=.000***

The differences between caregivers reporting or not own health condition could not be examined in: Germany as there were 9 caregivers who declared no health condition; Ireland as there were 17 caregivers who declared no health condition. *p < .05; **p < .01; ***p < .001

Table 6 The effect of care recipient's health condition on key study variables

	Country	**Greece**			**Israel**			**Italy**			**Netherlands**			**Poland**			**Sweden**			**UK**			**Total sample**		
Scale	Number of CR health condition(s) Subscale	Single N=38	Multimorbidity N=39	t p value	Single N=45	Multimorbidity N=69	t p value	Single N=98	Multimorbidity N=82	t p value	Single N=69	Multimorbidity N=115	t p value	Single N=22	Multimorbidity N=46	t p value	Single N=35	Multimorbidity N=53	t p value	Single N=42	Multimorbidity N=93	t p value	Single N=374	Multimorbidity N=538	t p value
RFS	Total score	41.36 (11.60)	43.17 (10.83)	t=-.70 p=.481	48.55 (8.77)	49.04 (9.97)	t=-.26 p=.790	42.81 (10.58)	44.30 (12.44)	t=-.86 p=.387	40.91 (10.36)	39.04 (9.92)	t=1.21 p=.225	45.09 (12.19)	44.36 (9.44)	t=.26 p=.790	36.17 (12.17)	35.41 (10.87)	t=.30 p=.762	42.45 (8.19)	44.82 (7.99)	t=-1.58 p=.115	42.34 (10.72)	42.95 (10.94)	t=-.83 p=.405
	Familial interconnectedness	27.07 (6.67)	27.94 (6.24)	t=-.59 p=.556	32.73 (6.02)	32.56 (6.08)	t=.14 p=.885	28.89 (6.44)	29.63 (7.64)	t=-.70 p=.484	28.79 (6.32)	27.28 (6.07)	t=1.60 p=.110	29.22 (7.13)	29.32 (5.31)	t=-.06 p=.949	25.74 (7.27)	24.81 (6.51)	t=.62 p=.532	28.42 (4.81)	29.62 (5.01)	t=-1.29 p=.197	28.69 (6.53)	28.76 (6.57)	t=-.17 p=.865
	Family support	6.89 (3.23)	7.35 (2.81)	t=-.67 p=.504	8.04 (2.05)	8.17 (2.49)	t=-.29 p=.773	6.55 (2.87)	6.71 (3.02)	t=-.38 p=.703	6.28 (2.69)	5.79 (2.79)	t=1.18 p=.237	7.86 (3.13)	7.60 (2.89)	t=.33 p=.742	4.31 (3.22)	5.13 (3.15)	t=-1.17 p=.241	7.07 (2.25)	7.21 (2.40)	t=-.32 p=.744	6.63 (2.88)	6.84 (2.93)	t=-1.04 p=.295
	Familial obligations	7.34 (2.89)	7.87 (3.07)	t=-.77 p=.439	7.97 (2.94)	8.43 (2.97)	t=-.80 p=.422	7.50 (3.14)	7.90 (3.24)	t=-.84 p=.401	6.53 (2.27)	6.30 (2.92)	t=.56 p=.573	7.68 (3.90)	7.08 (3.02)	t=.68 p=.493	6.05 (3.09)	5.47 (2.72)	t=.93 p=.353	6.92 (2.67)	7.56 (2.63)	t=-1.30 p=.195	7.17 (2.95)	7.32 (3.11)	t=-.73 p=.464
IPQ	Illness threat	53.47 (9.42)	51.35 (7.66)	t=1.08 p=.283	54.71 (8.52)	52.56 (8.05)	t=1.35 p=.177	56.78 (9.62)	56.09 (8.60)	t=.50 p=.617	56.53 (8.46)	57.00 (7.48)	t=-.39 p=.694	61.63 (10.73)	55.8 (8.99)	t=2.31 p=.024*	59.37 (6.77)	56.96 (8.92)	t=1.35 p=.178	59.16 (9.44)	59.02 (8.32)	t=.09 p=.928	57.08 (9.21)	56.04 (8.51)	t=1.74 p=.081
MLQ	Presence of meaning	25.42 (5.11)	23.97 (4.94)	t=1.21 p=.211	26.44 (5.47)	26.28 (5.55)	t=.14 p=.884	23.62 (6.64)	23.06 (6.83)	t=.55 p=.578	23.81 (5.07)	24.22 (5.37)	t=-.51 p=.606	22.40 (8.16)	24.23 (6.47)	t=-1.00 p=.321	23.45 (6.18)	23.86 (7.16)	t=-.27 p=.782	22.88 (8.32)	22.74 (5.73)	t=.09 p=.922	23.91 (6.49)	23.86 (6.09)	t=.12 p=.899
	Search for meaning	23.10 (5.46)	23.41 (6.13)	t=-.23 p=.819	23.48 (7.21)	21.24 (7.53)	t=1.57 p=.117	19.80 (7.72)	19.36 (7.50)	t=38 p=.700	20.24 (5.97)	20.06(6.41)	t=.18 p=.853	25.45 (7.34)	25.54 (5.02)	t=-.05 p=.954	18.68 (7.15)	17.84 (7.74)	t=.51 p=.611	15.97 (7.52)	18.10 (6.32)	t=-1.70 p=.090	20.33 (7.49)	20.15 (7.19)	t=.36 p=.715
PVQ	Self-transcendence	1.91 (.67)	2.08 (.61)	t=-1.12 p=.263	2.20 (.76)	2.19 (.78)	t=.06 p=.945	2.15 (.69)	2.06 (.77)	t=.83 p=.407	2.22 (.57)	2.25 (.63)	t=-.38 p=.701	2.13 (.76)	2.11 (.58)	t=.13 p=.890	2.51 (.79)	2.16 (.64)	t=2.23 p=.028*	2.30 (.86)	2.14 (.74)	t=1.14 p=.253	2.19 (.72)	2.18 (.71)	t=.28 p=.777
	Self-enhancement	3.97 (1.14)	4.04 (1.10)	t=-.27 p=.782	3.38 (1.05)	3.46 (1.00)	t=-.36 p=.718	3.72 (1.01)	3.58 (1.09)	t=.91 p=.360	4.11 (.93)	4.09 (1.01)	t=.16 p=.870	4.44 (.87)	4.14 (.84)	t1.36 p=.177	4.34 (.88)	4.48 (.86)	t=-.72 p=.469	4.45 (.90)	4.26 (.89)	t=1.18 p=.238	4.00 (1.04)	4.00 (1.02)	t=.05 p=.959
MECS	EXMECS	27.36 (4.76)	29.46 (3.60)	t=-2.17 p=.033*	27.08 (5.33)	26.40 (5.29)	t=.67 p=.503	27.93 (4.75)	28.24 (5.27)	t=-.40 p=.684	27.08 (4.93)	26.26 (5.60)	t=1.01 p=.313	28.5 9 (3.62)	26.93 (5.41)	t=1.29 p=.198	29.31 (3.73)	28.41 (5.26)	t=.93 p=.352	27.66 (4.56)	28.13 (4.81)	t=-.53 p=.592	27.71 (4.75)	27.32 (5.29)	t=1.15 p=.248
	INMECS	25.36 (4.06)	25.38 (3.69)	t=-.01 p=.985	24.71 (3.52)	24.33 (4.21)	t=.49 p=.619	24.85 (3.94)	25.28 (4.44)	t=-.67 p=.499	25.02 (4.70)	25.13 (4.67)	t=-.15 p=.878	23.27 (6.10)	23.80 (4.76)	t=-.39 p=.696	23.57 (4.17)	24.24 (3.63)	t=-.80 p=.425	24.90 (3.90)	25.76 (3.46)	t=-1.28 p=.203	24.71 (4.25)	24.85 (4.28)	t=-.48 p=.629
WtC	Nursing care	4.12 (.99)	4.47 (.67)	t=-1.82 p=.073	3.83 (1.10)	3.83 (.93)	t=-.01 p=.985	4.49 (.68)	4.38 (.74)	t=.98 p=.326	4.25 (.97)	4.27 (.91)	t=-.17 p=.860	3.86 (.82)	3.97 (.86)	t=-.48 p=.629	3.03 (.96)	3.60 (.67)	t=-3.03 p=.004**	4.34 (.87)	4.37 (.67)	t=-.22 p=.821	4.12 (.98)	4.15 (.87)	t=-.46 p=.645

	Emotional care	4.20 (.95)	4.35 (.61)	t=-.84 p=.402	4.36 (.68)	4.48 (.54)	t=-1.05 p=.294	4.40 (.65)	4.35 (.62)	t=.54 p=.589	4.58 (.65)	4.58 (.62)	t=.04 p=.962	4.15 (.83)	4.00 (.75)	t=.72 p=.472	4.17 (.86)	4.35 (.70)	t=-1.09 p=.277	4.57 (.66)	4.55 (.56)	t=.17 p=.862	4.40 (.72)	4.41 (.67)	t=-.02 p=.978
	Instrumental care	4.37 (.75)	4.59 (.47)	t=-1.52 p=.132	4.36 (.72)	4.34 (.66)	t=.15 p=.879	4.57 (.56)	4.51 (.59)	t=.68 p=.491	4.41 (.72)	4.38 (.74)	t=.25 p=.798	4.19 (.74)	4.26 (.71)	t=-.37 p=.710	3.56 (.87)	3.86 (.44)	t=-1.87 p=.067	4.59 (.55)	4.61 (.50)	t=-.28 p=.774	4.39 (.73)	4.38 (.66)	t=.07 p=.944
	Global score	4.23 (.82)	4.44 (.48)	t=-1.33 p=.186	4.18 (.71)	4.22 (.62)	t=-.28 p=.779	4.48 (.53)	4.40 (.51)	t=.97 p=.332	4.42 (.66)	4.42 (.67)	t=-.04 p=.962	4.12 (.59)	4.08 (.68)	t=.24 p=.810	3.57 (.76)	3.94 (.45)	t=-2.54 p=.014*	4.46 (.56)	4.51 (.45)	t=-.57 p=.566	4.28 (.70)	4.30 (.62)	t=-.46 p=.641
WHO-5		45.26 (24.44)	42.76 (23.34)	t=.45 p=.648	61.24 (23.38)	58.14 (21.06)	t=.73 p=.464	38.77 (24.42)	41.95 (20.51)	t=-.93 p=.352	52.00 (23.19)	52.27 (23.84)	t=-.07 p=.938	26.18 (18.38)	32.34 (23.65)	t=-1.07 p=.286	42.62 (23.50)	44.67 (24.54)	t=-.39 p=.697	44.00 (27.18)	41.84 (21.48)	t=.45 p=.652	44.75 (25.28)	46.00 (23.50)	t=-.75 p=.451
GAINS		9.73 (6.59)	11.82 (6.65)	t=-1.38 p=.172	10.35 (6.67)	10.68 (6.58)	t=-.25 p=.798	10.59 (6.17)	11.15 (6.72)	t=-.58 p=.557	13.75 (5.89)	14.91 (6.46)	t=-1.21 p=.225	11.59 (6.55)	11.76 (5.98)	t=-.10 p=.916	14.34 (6.50)	16.11 (6.00)	t=-1.31 p=.194	15.64 (6.91)	16.94 (6.41)	t=-1.06 p=.288	12.27 (6.61)	13.79 (6.79)	t=-3.35 p=.001**
ZBI		21.94 (9.54)	23.38 (9.42)	t=-.66 p=.508	17.66 (9.95)	16.23 (7.84)	t=.85 p=.393	20.77 (9.29)	20.95 (8.66)	t=-.13 p=.896	19.31 (8.81)	18.00 (9.13)	t=.96 p=.338	23.50 (10.44)	22.17 (8.18)	t=.57 p=.570	24.71 (10.37)	23.60 (9.09)	t=.53 p=.597	20.42 (10.82)	23.39 (7.99)	t=-1.59 p=.116	20.73 (9.75)	20.79 (9.05)	t=-.10 p=.920
CES-D		11.39 (6.24)	13.17 (6.44)	t=-1.23 p=.221	9.08 (6.45)	8.82 (4.89)	t=.23 p=.816	13.17 (6.75)	12.74 (6.42)	t=.43 p=.665	10.26 (5.71)	9.62 (5.59)	t=.73 p=.461	14.09 (7.03)	13.86 (7.87)	t=.11 p=.911	12.88 (6.52)	12.45 (5.96)	t=.32 p=.749	12.38 (7.19)	12.83 (6.53)	t=-.36 p=.716	11.87 (6.67)	11.71 (6.33)	t=.38 p=.701
EQ-5D	Utility index	.81 (.16)	.80 (.16)	t=.14 p=.883	.89 (.12)	.89 (.09)	t=-.13 p=.892	.72 (.25)	.70 (.25)	t=.53 p=.592	.79 (.16)	.76 (.20)	t=.85 p=.393	.86 (.13)	.82 (.17)	t=.74 p=.459	.84 (.12)	.82 (.13)	t=.59 p=.554	.82 (.17)	.79 (.16)	t=.89 p=.373	.79 (.20)	.79 (.19)	t=.24 p=.810

The differences in care recipient’s number of health conditions could not be examined in: Germany as there were 6 caregivers reporting care recipient’s single health condition; Ireland as there were 19 caregivers reporting care recipient’s single health condition. *p < .05; **p < .01; ***p < .001

Table 7 The effect of previous caring experience on key study variables

	Country	**Greece**			**Israel**			**Italy**			**Netherlands**			**Poland**			**Sweden**			**UK**			**Total sample**		
Scale	Caring experience	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value
		N=46	N=34		N=80	N=45		N=125	N=62		N=74	N=115		N=45	N=24		N=63	N=27		N=75	N=64		N=547	N=399	
	Subscale																								
RFS	Total score	40.67	44.91	t=-1.70	49.03	48.40	t=.33	44.63	41.27	t=1.92	37.85	40.70	t=-1.90	43.04	48.04	t=-1.94	35.39	36.40	t=-.39	44.52	43.21	t=.89	42.64	42.87	t=-.33
		(11.52)	(10.19)	p=.092	(10.93)	(8.88)	p=.739	(11.36)	(10.99)	p=.056	(9.79)	(10.18)	p=.058	(10.69)	(9.00)	p=.056	(12.13)	(8.91)	p=.698	(8.35)	(8.72)	p=.371	(11.49)	(10.18)	p=.740
	Familial interconnectedness	26.65	28.88	t=-1.54	32.40	32.88	t=-.45	29.88	28.04	t=1.71	26.32	28.78	t=-2.71	29.06	29.83	t=-.51	24.95	25.81	t=-.55	29.60	28.67	t=1.04	28.59	29.02	t=-1.01
		(6.73)	(5.84)	p=.126	(6.94)	(4.97)	p=.650	(7.08)	(6.48)	p=.089	(6.11)	(6.03)	p=.007**	(6.21)	(5.26)	p=.609	(7.26)	(5.32)	p=.580	(4.90)	(5.54)	p=.297	(6.98)	(5.98)	p=.309
	Family support	6.60	7.73	t=-1.66	8.25	7.95	t=.61	6.84	6.43	t=.88	5.52	6.17	t=-1.57	7.17	8.79	t=-2.21	4.73	5.03	t=-.42	7.42	6.84	t=1.40	6.75	6.80	t=-.25
		(3.18)	(2.70)	p=.100	(2.55)	(2.54)	p=.537	(3.03)	(2.98)	p=.380	(2.78)	(2.74)	p=.118	(2.87)	(2.87)	p=.030*	(2.99)	(3.55)	p=.675	(2.37)	(2.50)	p=.161	(3.02)	(2.87)	p=.797
	Familial obligations	7.36	8.00	t=-.93	8.50	7.75	t=1.32	7.72	7.45	t=.54	6.17	6.40	t=-.55	6.64	8.75	t=-2.55	5.68	5.55	t=.19	7.48	7.09	t=.83	7.26	7.19	t=.35
		(2.84)	(3.17)	p=.354	(2.84)	(3.31)	p=.188	(3.26)	(3.05)	p=.590	(2.84)	(2.64)	p=.581	(3.42)	(2.92)	p=.013*	(3.05)	(2.45)	p=.849	(2.91)	(2.45)	p=.404	(3.16)	(2.97)	p=.725
IPQ	Illness threat	52.65	52.58	t=.03	53.22	52.24	t=.63	57.20	54.11	t=1.97	58.25	55.75	t=2.31	59.00	55.54	t=1.40	57.92	57.55	t=.19	60.48	57.43	t=2.02	57.10	55.20	t=3.21
		(8.36)	(8.92)	p=.974	(7.90)	(9.09)	p=.530	(8.67)	(10.72)	p=.052	(6.32)	(8.50)	p=.022*	(9.47)	(10.27)	p=.165	(8.44)	(7.66)	p=.847	(7.60)	(9.74)	p=.045*	(8.49)	(9.33)	p=.001**
MLQ	Presence of meaning	24.45	25.14	t=-.58	26.00	26.84	t=-.80	23.35	23.80	t=-.43	23.41	24.58	t=-1.50	23.44	24.04	t=-.33	22.96	25.22	t=-1.46	22.18	23.46	t=1.13	23.54	24.48	t=-2.31
		(5.53)	(4.67)	p=.558	(5.50)	(5.77)	p=.420	(6.84)	(6.38)	p=.663	(5.56)	(4.92)	p=.134	(6.93)	(7.27)	p=.739	(6.80)	(6.35)	p=.146	(6.72)	(6.52)	p=.258	(6.50)	(5.84)	p=.021*
	Search for meaning	23.26	23.32	t=-.04	22.27	22.53	t=-.18	19.68	19.30	t=.31	19.86	20.27	t=-.44	25.86	24.66	t=.81	18.55	17.22	t=.77	17.72	17.56	t=.13	20.31	20.23	t=.18
		(6.08)	(5.65)	p=.963	(7.50)	(7.79)	p=.856	(7.95)	(6.74)	p=.751	(6.50)	(5.98)	p=.655	(5.62)	(6.16)	p=.417	(7.64)	(6.99)	p=.439	(7.07)	(6.61)	p=.893	(7.59)	(6.94)	p=.855
PVQ	Self-transcendence	2.01	1.93	t=.52	2.27	2.06	t=1.48	2.15	2.03	t=1.01	2.41	2.13	t=3.25	2.16	2.05	t=.62	2.29	2.34	t=-.31	2.22	2.17	t=.37	2.23 (.74)	2.11 (.68)	t=2.67
		(.64)	(.66)	p=.599	(.79)	(.74)	p=.141	(.77)	(.66)	p=.311	(.65)	(.54)	p=.001**	(.61)	(.68)	p=.533	(.76)	(.61)	p=.752	(.72)	(.88)	p=.705			p=.008**
	Self-enhancement	4.01	4.11	t=-.39	3.42	3.41	t=.06	3.55	3.86	t=-1.92	4.07	4.13	t=-.40	4.22	4.29	t=-.31	4.46	4.34	t=.62	4.40	4.23	t=1.08	3.96	4.06	t=-1.46
		(1.07)	(1.20)	p=.693	(1.04)	(.95)	p=.952	(1.04)	(1.02)	p=.056	(.98)	(.98)	p=.688	(.90)	(.76)	p=.751	(.88)	(.83)	p=.532	(.89)	(.89)	p=.279	(1.05)	(1.00)	p=.142
MECS	EXMECS	28.45	28.17	t=.28	26.53	26.88	t=-.35	28.64	26.69	t=2.55	27.22	26.20	t=1.30	26.97	28.58	t=-1.29	28.90	28.37	t=.49	28.50	27.54	t=1.20	27.84	26.97	t=2.61
		(3.91)	(4.75)	p=.774	(5.13)	(5.44)	p=.720	(4.73)	(5.22)	p=.011*	(4.77)	(5.61)	p=.194	(4.90)	(4.92)	p=.200	(4.48)	(5.18)	p=.622	(4.69)	(4.66)	p=.230	(4.75)	(5.38)	p=.009**
	INMECS	25.21	25.67	t=-.51	24.16	25.11	t=-1.30	25.25	24.41	t=1.27	25.60	24.71	t=1.27	22.91	24.95	t=-1.82	23.68	24.25	t=-.64	25.84	25.20	t=1.04	24.76	24.79	t=-.10
		(4.27)	(3.34)	p=.605	(3.93)	(3.88)	p=.196	(4.29)	(4.03)	p=.203	(3.77)	(5.19)	p=.202	(5.75)	(3.51)	p=.072	(3.99)	(3.69)	p=.523	(3.18)	(4.03)	p=.300	(4.20)	(4.39)	p=.916
WtC	Nursing care	4.24	4.42	t=-1.01	3.84	3.74	t=.54	4.47	4.38	t=.80	4.25	4.22	t=.16	3.96	3.88	t=.33	3.37	3.43	t=-.31	4.35	4.36	t=-.06	4.11 (.91)	4.16 (.94)	t=-.73
		(.93)	(.72)	p=.314	(1.02)	(1.01)	p=.588	(.65)	(.81)	p=.422	(.89)	(1.01)	p=.868	(.81)	(.92)	p=.738	(.76)	(1.00)	p=.754	(.80)	(.67)	p=.951			p=.465
	Emotional care	4.22	4.39	t=-.96	4.38	4.49	t=-.94	4.42	4.31	t=1.03	4.58	4.54	t=.43	4.04	4.05	t=-.02	4.35	4.15	t=1.11	4.55	4.58	t=-.30	4.39 (.68)	4.42 (.71)	t=-.70
		(.76)	(.82)	p=.336	(.65)	(.53)	p=.345	(.59)	(.71)	p=.301	(.63)	(.70)	p=.667	(.80)	(.73)	p=.978	(.70)	(.89)	p=.270	(.59)	(.59)	p=.764			p=.478
	Instrumental care	4.50	4.50	t=.000	4.33	4.36	t=-.25	4.60	4.42	t=1.78	4.41	4.32	t=.78	4.28	4.13	t=.78	3.77	3.69	t=.49	4.65	4.54	t=1.21	4.39 (.68)	4.35 (.73)	t=.97
		(.54)	(.72)	p=1.000	(.70)	(.68)	p=.799	(.50)	(.69)	p=.078	(.78)	(.77)	p=.432	(.70)	(.74)	p=.436	(.60)	(.76)	p=.622	(.50)	(.53)	p=.226			p=.332
	Global score	4.32	4.40	t=-.53	4.18	4.19	t=-.09	4.48	4.38	t=1.09	4.42	4.37	t=.45	4.12	4.02	t=.61	3.83	3.74	t=.62	4.50	4.50	t=.01	4.29 (.64)	4.29 (.70)	t=-.15
		(.65)	(.70)	p=.597	(.70)	(.62)	p=.923	(.47)	(.62)	p=.277	(.66)	(.74)	p=.648	(.64)	(.67)	p=.541	(.54)	(.76)	p=.534	(.50)	(.46)	p=.987			p=.875
WHO-5		44.34	45.41	t=-.20	60.90	60.44	t=.11	39.68	41.74	t=-.58	50.37	53.63	t=-.92	31.55	29.16	t=.42	43.11	45.62	t=-.45	41.22	44.68	t=-.86	44.68	47.82	t=-1.96
		(25.54)	(21.59)	p=.841	(22.00)	(22.06)	p=.912	(21.91)	(24.36)	p=.560	(22.76)	(24.08)	p=.355	(22.35)	(22.27)	p=.673	(23.84)	(24.28)	p=.649	(23.03)	(23.86)	p=.387	(24.15)	(24.49)	p=.050
GAINS		11.80	9.05	t=1.84	10.43	10.11	t=.26	10.72	11.01	t=-.29	15.16	13.97	t=1.27	12.00	10.87	t=.72	15.07	15.88	t=-.56	16.98	15.96	t=.90	13.16	12.92	t=.53
		(6.95)	(5.98)	p=.068	(6.14)	(7.42)	p=.792	(6.09)	(6.96)	p=.766	(5.97)	(6.41)	p=.203	(6.33)	(5.80)	p=.472	(6.25)	(6.17)	p=.574	(6.96)	(6.10)	p=.365	(6.73)	(6.83)	p=.590
ZBI		23.26	20.88	t=1.10	16.63	16.77	t=-.08	21.46	19.38	t=1.51	19.36	17.83	t=1.14	23.80	21.12	t=1.16	24.52	22.44	t=.94	22.90	22.04	t=.54	21.48	19.54	t=3.16
		(10.22)	(8.46)	p=.273	(8.08)	(9.36)	p=.930	(8.38)	(9.73)	p=.133	(9.08)	(8.89)	p=.254	(8.61)	(9.97)	p=.249	(9.38)	(9.86)	p=.345	(9.04)	(9.38)	p=.584	(9.20)	(9.39)	p=.002**
CES-D		12.39	11.79	t=.41	8.77	8.88	t=-.10	12.90	12.50	t=.39	10.00	9.65	t=.41	14.28	13.20	t=.56	12.47	12.62	t=-.10	13.05	12.09	t=.83	11.99	11.16	t=1.95
		(6.84)	(5.70)	p=.680	(5.75)	(5.47)	p=.914	(6.51)	(6.90)	p=.696	(5.97)	(5.41)	p=.679	(7.20)	(8.16)	p=.573	(5.77)	(7.15)	p=.915	(6.46)	(7.11)	p=.407	(6.49)	(6.45)	p=.051
EQ-5D	Utility index	.78	.86	t=-2.41	.89	.89	t=.27	.71	.71	t=-.09	.80	.76	t=1.15	.84	.83	t=.26	.82	.85	t=-.89	.81	.79	t=.73	.79 (.19)	.79 (.19)	t=.26
		(.18)	(.11)	p=.018*	(.11)	(.10)	p=.783	(.25)	(.25)	p=.927	(.16)	(.20)	p=.251	(.16)	(.16)	p=.791	(.12)	(.13)	p=.372	(.16)	(.17)	p=.464			p=.788

The differences in caring experience could not be examined in: Germany as there were 9 caregivers reporting any previous caring experience; Ireland as there were 19 caregivers reporting any previous caring experience. *p < .05; **p < .01; ***p < .001

Table 8 The effect of caregiver-care recipient relationship type on key study variables

	Country	Italy				Netherlands				UK				Total sample			
Scale	Relationship type	spouse/partner	parent/parent-in-law	Other	F p value	spouse/partner	parent/parent-in-law	Other	F p value	spouse/partner	parent/parent-in-law	Other	F p value	spouse/partner	parent/parent-in-law	Other	F p value
		N=44	N=106	N=37		N=84	N=66	N=39		N=57	N=52	N=30		N=305	N=433	N=208	
	Subscale																
RFS	Total score	41.52 (13.49)	44.70 (10.71)	42.48 (10.01)	F=1.42 p=.243	39.23 (10.57)	40.83 (8.36)	38.23 (11.69)	F=.90 p=.407	44.70 (8.02)	44.59 (8.98)	41.26 (8.35)	F=1.88 p=.156	41.21 (11.36)	44.05 (10.45)	42.23 (11.08)	F=6.37 p=.002**
	Familial interconnectedness	28.45 (8.42)	30.00 (6.39)	28.13 (6.34)	F=1.41 p=.247	27.47 (6.53)	28.46 (5.47)	27.46 (6.54)	F=.56 p=.572	29.63 (4.73)	29.69 (5.77)	27.40 (4.81)	F=2.25 p=.109	27.93 (6.88)	29.48 (6.33)	28.54 (6.50)	F=5.14 p=.006**
	Family support	6.15 (3.42)	6.96 (2.81)	6.64 (3.04)	F=1.11 p=.331	5.60 (2.84)	6.15 (2.47)	6.20 (3.07)	F=.97 p=.381	7.22 (2.17)	7.46 (2.76)	6.50 (2.27)	F=1.52 p=.221	6.28 (3.07)	7.16 (2.86)	6.69 (2.88)	F=8.08 p=.000***
	Familial obligations	7.45 (3.52)	7.74 (3.14)	7.51 (2.98)	F=.15 p=.853	6.48 (2.83)	6.42 (2.54)	5.74 (2.75)	F=1.08 p=.340	7.45 (2.63)	7.44 (2.63)	6.76 (2.99)	F=.74 p=.477	7.08 (3.02)	7.44 (3.03)	7.03 (3.23)	F=1.81 p=.164
IPQ	Illness threat	56.97 (7.61)	56.34 (9.94)	54.72 (10.20)	F=.60 p=.549	59.11 (6.31)	55.80 (7.44)	53.17 (9.60)	F=9.17 p=.000***	59.59 (7.05)	57.86 (9.54)	60.20 (10.18)	F=.84 p=.432	58.09 (7.55)	55.75 (9.05)	54.83 (9.98)	F=10.05 p=.000
MLQ	Presence of meaning	22.29 (6.28)	23.42 (7.08)	25.16 (5.68)	F=1.88 p=.155	23.45 (5.50)	24.56 (4.80)	24.84 (5.15)	F=1.31 p=.272	22.85 (6.02)	22.76 (6.78)	22.63 (7.66)	F=.01 p=.989	23.25 (6.26)	24.30 (6.20)	24.19 (6.26)	F=2.72 p=.066
	Search for meaning	18.70 (7.25)	20.20 (7.66)	18.70 (7.61)	F=.90 p=.405	20.32 (6.14)	20.42 (6.03)	19.15 (6.54)	F=.59 p=.551	17.59 (6.25)	17.48 (7.39)	18.03 (7.14)	F=.06 p=.938	19.36 (7.20)	21.03 (7.23)	20.06 (7.54)	F=4.81 p=.008**
PVQ	Self-transcendence	2.04 (0.68)	2.03 (0.75)	2.41 (0.70)	F=3.85 p=.023*	2.29 (0.61)	2.22 (0.55)	2.15 (0.67)	F=.76 p=.469	2.36 (0.87)	2.09 (0.75)	2.09 (0.67)	F=1.93 p=.149	2.26 (0.74)	2.12 (0.70)	2.19 (0.71)	F=3.53 p=.030*
	Self-enhancement	3.46 (1.01)	3.60 (1.00)	4.01 (1.13)	F=3.05 p=.050	4.07 (0.98)	4.15 (0.97)	4.12 (1.02)	F=.15 p=.861	4.47 (0.82)	4.07 (0.93)	4.48 (0.86)	F=3.38 p=.037*	4.10 (0.98)	3.89 (1.02)	4.08 (1.09)	F=4.56 p=.011*
MECS	EXMECS	27.29 (5.81)	28.32 (4.68)	27.89 (4.73)	F=.66 p=.514	26.97 (5.24)	26.74 (5.13)	25.56 (5.76)	F=.97 p=.379	28.21 (5.15)	28.17 (4.47)	27.60 (4.19)	F=.18 p=.830	27.73 (5.31)	27.87 (4.59)	26.25 (5.35)	F=7.95 p=.000***
	INMECS	24.95 (4.55)	24.82 (4.35)	25.45 (3.39)	F=.31 p=.732	26.20 (4.75)	24.10 (4.51)	24.23 (4.46)	F=4.61 p=.011*	26.01 (3.39)	25.30 (3.91)	25.06 (3.40)	F=.86 p=.422	25.28 (4.45)	24.58 (4.32)	24.46 (3.88)	F=3.17 p=.042*
WtC	Nursing care	4.32 (0.81)	4.47 (0.64)	4.47 (0.77)	F=.80 p=.449	4.45 (0.81)	4.12 (0.85)	3.96 (1.32)	F=4.11 p=.018*	4.52 (0.62)	4.26 (0.76)	4.21 (0.89)	F=2.38 p=.096	4.25 (0.81)	4.13 (0.91)	3.95 (1.08)	F=6.65 p=.001**
	Emotional care	4.40 (0.63)	4.31 (0.67)	4.56 (0.46)	F=2.13 p=.121	4.61 (0.61)	4.58 (0.59)	4.39 (0.91)	F=1.45 p=.236	4.60 (0.41)	4.56 (0.63)	4.52 (0.78)	F=.18 p=.835	4.48 (0.63)	4.35 (0.69)	4.40 (0.77)	F=3.24 p=.039*
	Instrumental care	4.64 (0.51)	4.47 (0.61)	4.60 (0.54)	F=1.52 p=.220	4.71 (0.59)	4.13 (0.62)	3.98 (1.00)	F=19.51 p=.000***	4.75 (0.42)	4.59 (0.48)	4.35 (0.64)	F=6.32 p=.002**	4.56 (0.58)	4.36 (0.67)	4.15 (0.84)	F=21.98 p=.000***
	Global score	4.39 (0.59)	4.44 (0.51)	4.51 (0.49)	F=.47 p=.624	4.60 (0.58)	4.29 (0.58)	4.13 (1.00)	F=7.14 p=.001**	4.62 (0.39)	4.47 (0.46)	4.31 (0.60)	F=4.54 p=.012*	4.40 (0.60)	4.28 (0.64)	4.15 (0.78)	F=9.02 p=.000***
WHO-5		42.63 (22.57)	38.37 (22.10)	43.35 (24.57)	F=.94 p=.391	50.66 (22.01)	53.75 (22.98)	53.64 (27.81)	F=.38 p=.679	43.85 (22.39)	43.07 (23.27)	40.40 (25.99)	F=.21 p=.805	46.71 (23.36)	45.15 (24.42)	46.76 (25.57)	F=.49 p=.609
GAINS		10.63 (5.57)	11.56 (6.63)	8.89 (6.25)	F=2.47 p=.087	13.95 (6.60)	15.68 (6.42)	13.38 (4.82)	F=2.13 p=.121	16.31 (6.14)	16.01 (6.61)	17.76 (7.35)	F=.71 p=.492	13.72 (6.63)	12.97 (6.79)	12.26 (6.85)	F=2.96 p=.052
ZBI		18.97 (9.21)	22.12 (8.81)	19.05 (8.20)	F=2.87 p=.059	18.85 (8.54)	18.72 (8.36)	17.02 (10.81)	F=.60 p=.547	21.80 (8.93)	22.86 (8.32)	23.23 (11.09)	F=.29 p=.744	20.66 (9.14)	21.44 (9.13)	19.04 (9.83)	F=4.68 p=.009**
CES-D		12.20 (6.40)	13.56 (6.68)	11.16 (6.53)	F=2.03 p=.133	9.78 (4.82)	9.54 (6.05)	10.20 (6.52)	F=.16 p=.846	12.19 (6.20)	12.98 (7.33)	12.76 (6.95)	F=.19 p=.826	11.56 (5.83)	11.87 (6.83)	11.27 (6.68)	F=.63 p=.529
EQ-5D	Utility index	0.67 (0.28)	0.72 (0.23)	0.74 (0.27)	F=.98 p=.377	0.77 (0.21)	0.78 (0.17)	0.77 (0.17)	F=.12 p=.884	0.80 (0.16)	0.80 (0.16)	0.78 (0.19)	F=.13 p=.874	0.78 (0.20)	0.80 (0.19)	0.80 (0.20)	F=1.09 p=.333

The differences could not be examined in: Germany as there were 10 caregivers providing care to spouse/partner and 4 providing care to the other family member/friend; Greece as there were 7 caregivers providing care to spouse/partner; Ireland as there were 10 caregivers providing care to parent/parent-in-law; Israel as there were 19 caregivers providing care to spouse/partner; Poland as there were 11 caregivers providing care to spouse/partner; Sweden as there were 17 caregivers providing care to parent/parent-in-law. *p < .05; **p < .01; ***p < .001

Table 9 The effect of the caregiver-care recipient co-residency status (living together or apart) on key study variables

	Country	**Greece**			**Israel**			**Italy**			**Netherlands**			**Poland**			**Sweden**			**UK**			**Total sample**		
Scale	Co-residence	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value
	Subscale	N=37	N=43		N=82	N=43		N=62	N=125		N=87	N=102		N=29	N=40		N=26	N=64		N=42	N=97		N=382	N=564	
RFS	Total score	39.40 (10.75)	45.11 (10.84)	t=-2.35 p=.021*	48.69 (10.11)	49.02 (10.50)	t=-.17 p=.865	41.53 (11.34)	44.50 (11.23)	t=-1.69 p=.091	39.47 (10.14)	39.68 (10.12)	t=-.14 p=.885	45.10 (10.76)	44.55 (10.17)	t=.21 p=.828	32.00 (8.65)	37.20 (11.84)	t=-2.02 p=.046*	43.35 (7.97)	44.16 (8.77)	t=-.51 p=.610	42.25 (11.00)	43.06 (10.90)	t=-1.11 p= .263
	Familial interconnectedness	25.94 (6.34)	29.02 (6.22)	t=-2.18 p=.032*	32.41 (6.43)	32.88 (6.07)	t=-.39 p=.694	28.24 (7.02)	29.78 (6.85)	t=-1.43 p=.152	28.11 (6.14)	27.56 (6.21)	t=.60 p=.545	29.79 (5.96)	29.00 (5.85)	t=.55 p=.584	23.65 (5.18)	25.84 (7.20)	t=-1.40 p=.163	29.50 (4.81)	29.03 (5.39)	t=.48 p=.628	28.78 (6.61)	28.77 (6.55)	t= .01 p= .987
	Family support	6.13 (2.82)	7.90 (2.98)	t=-2.71 p=.008**	8.03 (2.23)	8.34 (3.08)	t=-.58 p=.559	6.38 (2.59)	6.87 (3.20)	t=-1.03 p=.302	6.05 (2.70)	5.80 (2.83)	t=.62 p=.532	7.41 (3.02)	7.97 (2.92)	t=-.77 p=.441	4.03 (2.87)	5.14 (3.23)	t=-1.51 p=.134	6.52 (2.32)	7.43 (2.44)	t=-2.03 p=.043*	6.62 (2.79)	6.88 (3.06)	t= -1.30 p= .193
	Familial obligations	7.05 (2.91)	8.13 (2.98)	t=-1.63 p=.105	8.35 (3.15)	8.00 (2.80)	t=.61 p=.537	7.40 (3.07)	7.74 (3.25)	t=-.68 p=.493	6.12 (2.74)	6.47 (2.69)	t=-.86 p=.387	6.96 (3.78)	7.67 (3.09)	t=-.85 p=.395	4.30 (2.47)	6.18 (2.86)	t=-2.93 p=.004**	6.90 (2.78)	7.47 (2.67)	t=-1.13 p=.257	7.00 (3.17)	7.39 (3.00)	t= -1.94 p= .051
IPQ	Illness threat	51.78 (7.35)	53.34 (9.49)	t=-.83 p=.409	52.26 (8.80)	54.02 (7.30)	t=-1.18 p=.238	54.82 (10.41)	56.84 (8.95)	t=-1.37 p=.170	54.82 (8.34)	58.36 (6.94)	t=-3.17 p=.002**	55.20 (11.59)	59.67 (7.95)	t=-1.79 p=.080	58.46 (8.74)	57.54 (7.98)	t=.47 p=.633	57.21 (9.54)	59.88 (8.30)	t=-1.66 p=.099	54.49 (9.26)	57.53 (8.42)	t= 5.11 p= .000
MLQ	Presence of meaning	23.24 (4.75)	26.04 (5.20)	t=-2.49 p=.015*	26.60 (4.99)	25.72 (6.62)	t=.77 p=.443	24.59 (5.63)	22.96 (7.10)	t=1.58 p=.115	24.57 (4.91)	23.74 (5.43)	t=1.09 p=.276	25.55 (7.21)	22.27 (6.60)	t=1.95 p=.054	24.92 (7.09)	23.12 (6.54)	t=1.15 p=.252	24.23 (5.91)	22.14 (6.86)	t=1.71 p=.088	24.83 (5.70)	23.33 (6.51)	t= 3.63 p= .000***
	Search for meaning	23.18 (5.58)	23.37 (6.16)	t=-.13 p=.890	22.37 (7.29)	22.34 (8.19)	t=.02 p=.984	19.24 (7.03)	19.71 (7.83)	t=-.39 p=.690	20.19 (6.48)	20.04 (5.93)	t=.16 p=.872	26.75 (5.52)	24.50 (5.87)	t=1.61 p=.111	16.23 (7.40)	18.93 (7.36)	t=-1.57 p=.118	18.33 (6.43)	17.35 (7.02)	t=.77 p=.439	20.64 (7.19)	20.03 (7.39)	t= 1.25 p= .209
PVQ	Self-transcendence	1.89 (.58)	2.05 (.69)	t=-1.05 p=.293	2.20 (.77)	2.18 (.80)	t=.19 p=.848	2.13 (.69)	2.10 (.76)	t=.24 p=.806	2.20 (.58)	2.27 (.62)	t=-.79 p=.430	1.96 (.54)	2.24 (.68)	t=-1.78 p=.078	2.28 (.75)	2.32 (.71)	t=-.22 p=.826	2.09 (.69)	2.25 (.83)	t=-1.09 p=.276	2.16 (.68)	2.20 (.74)	t= -.89 p= .371
	Self-enhancement	4.15 (1.13)	3.97 (1.12)	t=.70 p=.482	3.34 (.98)	3.57 (1.04)	t=-1.21 p=.225	3.60 (1.02)	3.67 (1.06)	t=-.42 p=.672	4.11 (1.03)	4.11 (.94)	t=-.02 p=.983	4.35 (.68)	4.16 (.95)	t=.88 p=.380	4.72 (.93)	4.31 (.81)	t=2.06 p=.042*	3.95 (.91)	4.48 (.83)	t=-3.32 p=.001**	3.90 (1.05)	4.07 (1.01)	t= -2.51 p= .011*
MECS	EXMECS	27.70 (5.04)	28.88 (3.42)	t=-1.20 p=.233	26.02 (4.83)	27.88 (5.77)	t=-1.90 p=.059	27.19 (5.14)	28.39 (4.85)	t=-1.55 p=.121	25.57 (5.55)	27.48 (4.95)	t=-2.49 p=.014*	26.17 (5.33)	28.52 (4.43)	t=-1.99 p=.050	28.07 (5.06)	29.01 (4.52)	t=-.86 p=.391	27.90 (4.73)	28.13 (4.68)	t=-.26 p=.792	26.56 (5.18)	28.09 (4.84)	t= -4.63 p= .000***
	INMECS	25.43 (3.86)	25.39 (3.95)	t=.042 p=.966	23.98 (3.89)	25.48 (3.83)	t=-2.05 p=.042*	24.16 (4.02)	25.38 (4.26)	t=-1.87 p=.062	23.91 (4.74)	26.03 (4.46)	t=-3.16 p=.002**	23.20 (4.32)	23.92 (5.72)	t=-.56 p=.572	23.42 (4.11)	24.03 (3.82)	t=-.66 p=.506	24.30 (4.25)	26.08 (3.15)	t=-2.72 p=.007**	23.95 (4.25)	25.34 (4.20)	t= -4.97 p= .000***
WtC	Nursing care	4.22 (.90)	4.40 (.79)	t=-.94 p=.348	3.69 (1.05)	4.02 (.92)	t=-1.77 p=.079	4.35 (.77)	4.48 (.67)	t=-1.15 p=.249	4.03 (1.05)	4.41 (.84)	t=-2.71 p=.007**	3.74 (.81)	4.07 (.85)	t=-1.60 p=.113	3.01 (1.08)	3.54 (.66)	t=-2.31 p=.027*	3.96 (.88)	4.52 (.60)	t=-3.73 p=.000***	3.90 (1.03)	4.29 (.81)	t= -6.46 p= .000***
	Emotional care	4.27 (.87)	4.31 (.71)	t=-.25 p=.799	4.39 (.61)	4.48 (.60)	t=-.78 p=.433	4.31 (.73)	4.42 (.58)	t=-1.11 p=.268	4.52 (.74)	4.59 (.62)	t=-.72 p=.468	3.94 (.72)	4.12 (.80)	t=-.95 p=.341	4.25 (.92)	4.31 (.70)	t=-.30 p=.761	4.49 (.70)	4.60 (.53)	t=-1.07 p=.284	4.34 (.76)	4.45 (.64)	t= -2.41 p= .015*
	Instrumental care	4.35 (.71)	4.62 (.50)	t=-1.94 p=.056	4.18 (.74)	4.64 (.45)	t=-4.27 p=.000***	4.27 (.69)	4.67 (.46)	t=-4.10 p=.000***	4.05 (.77)	4.62 (.67)	t=-5.26 p=.000***	3.96 (.63)	4.42 (.71)	t=-2.69 p=.009**	3.41 (.86)	3.88 (.50)	t=-2.56 p=.015*	4.32 (.61)	4.72 (.42)	t=-3.89 p=.000***	4.11 (.77)	4.56 (.58)	t= -9.61 p= .000***
	Global score	4.28 (.77)	4.41 (.57)	t=-.88 p=.381	4.08 (.71)	4.38 (.54)	t=-2.38 p=.019*	4.35 (.56)	4.49 (.50)	t=-1.81 p=.072	4.22 (.78)	4.54 (.61)	t=-3.21 p=.002**	3.89 (.56)	4.23 (.68)	t=-2.16 p=.034*	3.56 (.80)	3.90 (.49)	t=-2.00 p=.053	4.25 (.55)	4.60 (.40)	t=-3.75 p=.000***	4.12 (.73)	4.41 (.59)	t= -6.25 p= .000***
WHO-5		42.81 (23.09)	46.51 (24.54)	t=-.69 p=.492	62.87 (21.16)	56.65 (23.02)	t=1.51 p=.132	40.38 (21.90)	40.35 (23.19)	t=.01 p=.992	56.41 (24.54)	48.90 (22.23)	t=2.20 p=.029*	36.96 (25.04)	26.20 (18.93)	t=2.03 p=.046*	39.53 (19.54)	45.62 (25.34)	t=-1.22 p=.226	46.28 (24.13)	41.31 (23.04)	t=1.15 p=.252	49.84 (24.61)	43.41 (23.77)	t= 4.01 p= .000***
GAINS		11.24 (6.23)	10.11 (7.04)	t=.75 p=.454	10.01 (6.56)	10.90 (6.72)	t=-.71 p=.474	11.32 (6.13)	10.56 (6.50)	t=.76 p=.448	15.05 (6.38)	13.91 (6.12)	t=1.25 p=.210	11.72 (6.50)	11.52 (5.93)	t=.13 p=.895	15.84 (5.17)	15.10 (6.61)	t=.50 p=.613	16.95 (7.00)	16.32 (6.41)	t=.51 p=.610	13.04 (6.76)	13.07 (6.76)	t= -.06 p= .949
ZBI		20.45 (8.77)	23.79 (9.98)	t=-1.57 p=.120	15.39 (7.60)	19.16 (9.68)	t=-2.22 p=.030*	20.74 (9.34)	20.79 (8.68)	t=-.03 p=.971	17.22 (9.10)	19.46 (8.77)	t=-1.71 p=.089	21.27 (9.60)	24.02 (8.71)	t=-1.24 p=.219	22.26 (9.07)	24.56 (9.68)	t=-1.03 p=.303	19.76 (8.94)	23.70 (9.06)	t=-2.36 p=.020*	18.79 (8.99)	21.93 (9.32)	t= -5.14 p=.000***
CES-D		12.24 (5.90)	12.04 (6.78)	t=.13 p=.891	7.87 (5.06)	10.60 (6.27)	t=-2.63 p=.010*	12.12 (6.29)	13.08 (6.78)	t=-.93 p=.353	9.24 (6.10)	10.25 (5.16)	t=-1.23 p=.218	12.27 (8.10)	15.10 (6.91)	t=-1.55 p=.124	12.38 (6.36)	12.57 (6.15)	t=-.13 p=.894	11.16 (6.21)	13.23 (6.93)	t=-1.66 p=.098	10.46 (6.27)	12.43 (6.50	t= -4.63 p= .000***
EQ-5D	Utility index	.83 (.12)	.80 (.19)	t=.85 p=.394	.91 (.10)	.85 (.12)	t=3.03 p=.003**	.75 (.23)	.69 (.25)	t=1.41 p=.160	.78 (.18)	.77 (.20)	t=.61 p=.542	.88 (.10)	.80 (.18)	t=2.38 p=.020*	.82 (.16)	.84 (.11)	t=-.57 p=.569	.84 (.11)	.78 (.18)	t=1.95 p=.052	.83 (.16)	.77 (.21)	t=4.94 p=.000***

The differences could not be examined in: Germany as there were 11 not co-residing with their recipient; Ireland as there were only 6 caregivers not co-residing with their care recipients.
*p < .05; **p < .01; ***p < .001

Table 10 The effect of care recipient's health condition on key study variables

	Country	**Greece**				**Israel**				**Italy**				**Netherlands**				**Sweden**				**UK**				**Total sample**			
Scale	CR's health condition Subscale	Physical N=31	Neurological N=28	Both N=21	F p value	Physical N=65	Neurological N=26	Both N=34	F p value	Physical N=74	Neurological N=62	Both N=51	F p value	Physical N=86	Neurological N=35	Both N=68	F p value	Physical N24	Neurological N=31	Both N=35	F p value	Physical N=60	Neurological N=25	Both N=54	F p value	Physical N=397	Neurological N=237	Both N=311	F p value
RFS	Total score	41.51 (9.06)	43.39 (13.98)	42.66 (9.87)	F=.21 p=.811	49.47 (11.07)	48.26 (7.57)	47.94 (10.41)	F=.29 p=.745	43.93 (11.35)	42.51 (10.51)	44.13 (12.34)	F=.36 p=.694	39.63 (10.42)	40.11 (8.50)	39.25 (10.57)	F=.08 p=.918	38.37 (11.22)	34.22 (11.75)	35.17 (10.73)	F=.98 p=.377	43.83 (8.66)	42.64 (8.80)	44.61 (8.31)	F=.45 p=.633	43.37 (10.97)	42.02 (11.04)	42.44 (10.87)	F=1.28 p=.277
	Familial interconnectedness	26.87 (4.82)	28.25 (8.12)	27.80 (6.13)	F=.34 p=.707	32.92 (6.84)	32.46 (5.15)	32.00 (6.10)	F=.24 p=.785	29.13 (7.32)	28.96 (5.98)	29.84 (7.48)	F=.24 p=.783	27.79 (6.33)	28.17 (5.62)	27.67 (6.30)	F=.07 p=.927	26.83 (6.34)	24.61 (7.20)	24.62 (6.53)	F=.95 p=.390	29.21 (5.03)	28.28 (5.26)	29.53 (5.42)	F=.49 p=.609	29.04 (6.64)	28.47 (6.55)	28.63 (6.52)	F=.65 p=.521
	Family support	6.74 (2.58)	7.39 (3.75)	7.19 (2.60)	F=.35 p=.705	8.50 (2.55)	7.96 (1.90)	7.58 (2.89)	F=1.55 p=.216	6.45 (3.27)	6.88 (2.76)	6.86 (2.95)	F=.42 p=.655	6.02 (2.80)	6.02 (2.47)	5.73 (2.90)	F=.23 p=.791	5.95 (3.27)	3.96 (3.15)	4.80 (2.90)	F=2.79 p=.066	7.31 (2.59)	7.24 (1.96)	6.94 (2.49)	F=.34 p=.709	6.97 (2.98)	6.64 (2.94)	6.61 (2.94)	F=1.63 p=.196
	Familial obligations	7.58 (2.93)	7.67 (3.24)	7.66 (2.85)	F=.009 p=.991	8.32 (3.03)	7.84 (2.70)	8.35 (3.31)	F=.26 p=.768	7.68 (3.24)	7.25 (3.00)	8.00 (3.34)	F=.77 p=.462	6.39 (2.64)	6.14 (2.04)	6.29 (3.11)	F=.10 p=.897	5.50 (3.16)	5.64 (2.90)	5.74 (2.71)	F=.05 p=.951	7.28 (2.88)	7.12 (2.36)	7.40 (2.70)	F=.09 p=.907	7.34 (3.13)	7.03 (2.90)	7.26 (3.14)	F=.74 p=.475
IPQ	Illness threat	53.32 (7.87)	52.25 (9.84)	52.09 (8.00)	F=.16 p=.847	50.63 (8.04)	57.46 (7.50)	53.64 (8.09)	F=7.07 p=.001**	54.44 (9.44)	57.69 (10.17)	56.84 (8.39)	F=2.17 p=.116	56.50 (7.55)	57.22 (8.88)	56.77 (7.63)	F=.10 p=.897	55.58 (9.17)	59.03 (7.69)	58.25 (7.78)	F=1.29 p=.278	56.51 (9.44)	62.80 (7.49)	60.20 (7.71)	F=5.62 p=.004**	54.72 (8.95)	58.11 (9.20)	56.96 (8.27)	F=12.33 p=.000***
MLQ	Presence of meaning	25.83 (5.28)	24.78 (4.93)	23.09 (5.09)	F=1.80 p=.172	26.95 (5.31)	25.92 (5.88)	25.35 (5.90)	F=.99 p=.375	24.52 (5.70)	23.08 (7.21)	22.52 (7.22)	F=1.54 p=.216	23.98 (5.11)	23.94 (5.42)	24.39 (5.27)	F=.14 p=.867	24.50 (7.43)	24.70 (4.98)	22.11 (7.41)	F=1.50 p=.227	23.25 (5.94)	22.56 (8.67)	22.35 (6.40)	F=.27 p=.761	24.50 (5.90)	23.78 (6.68)	23.32 (6.29)	F=3.25 p=.039*
	Search for meaning	22.58 (6.19)	23.85 (4.84)	23.57 (6.74)	F=.37 p=.688	23.67 (7.26)	22.07 (7.64)	20.08 (7.77)	F=2.59 p=.079	19.08 (7.09)	20.66 (8.21)	18.90 (7.39)	F=.99 p=.370	20.13 (5.65)	20.45 (7.30)	19.91 (6.27)	F=.09 p=.914	17.79 (7.82)	18.64 (7.13)	17.97 (7.63)	F=.10 p=.901	18.21 (6.94)	14.76 (7.05)	18.35 (6.39)	F=2.78 p=.065	20.75 (7.26)	20.06 (7.73)	19.89 (7.04)	F=1.36 p=.256
PVQ	Self-transcendence	1.80 (0.60)	1.97 (0.65)	2.24 (0.64)	F=3.14 p=.049*	2.07 (0.74)	2.34 (0.76)	2.33 (0.84)	F=1.87 p=.158	2.16 (0.84)	2.12 (0.63)	2.01 (0.69)	F=.60 p=.549	2.24 (0.66)	2.24 (0.50)	2.24 (0.58)	F=.001 p=.999	2.26 (0.75)	2.59 (0.77)	2.09 (0.57)	F=4.34 p=.016*	2.27 (0.92)	2.30 (0.77)	2.07 (0.63)	F=1.16 p=.316	2.15 (.77)	2.23 (.68)	2.18 (.67)	F=1.06 p=.344
	Self-enhancement	4.09 (1.03)	3.95 (1.36)	4.14 (0.92)	F=.19 p=.826	3.34 (1.05)	3.45 (0.97)	3.55 (0.95)	F=.47 p=.626	3.72 (0.96)	3.60 (1.06)	3.61 (1.14)	F=.28 p=.755	4.04 (0.89)	4.14 (1.03)	4.18 (1.08)	F=.38 p=.681	4.42 (0.85)	4.34 (0.87)	4.50 (0.88)	F=.27 p=.759	4.22 (0.84)	4.39 (0.91)	4.41 (0.94)	F=.75 p=.471	3.95 (.99)	3.99 (1.07)	4.07 (1.04)	F=1.28 p=.278
MECS	EXMECS	27.64 (5.00)	28.25 (3.97)	29.47 (3.28)	F=1.16 p=.316	25.96 (5.37)	27.84 (4.20)	27.08 (5.57)	F=1.35 p=.261	27.22 (5.22)	28.00 (4.61)	29.09 (4.90)	F=2.15 p=.119	26.89 (5.43)	27.00 (5.28)	26.02 (5.20)	F=.62 p=.538	26.83 (6.23)	28.83 (3.71)	29.97 (3.83)	F=3.38 p=.038*	28.20 (4.26)	26.96 (5.54)	28.42 (4.72)	F=.87 p=.418	26.87 (5.25)	28.01 (4.44)	27.85 (5.11)	F=5.06 p=.007**
	INMECS	25.45 (4.34)	25.85 (3.72)	24.76 (3.46)	F=.47 p=.626	24.50 (3.80)	25.03 (3.36)	24.08 (4.56)	F=.42 p=.653	25.54 (3.97)	24.04 (4.35)	25.29 (4.29)	F=2.34 p=.099	25.68 (4.95)	24.31 (4.35)	24.66 (4.50)	F=1.45 p=.237	23.54 (4.42)	24.03 (3.96)	23.91 (3.55)	F=.11 p=.895	25.48 (3.25)	24.56 (4.65)	26.07 (3.37)	F=1.54 p=.218	25.14 (4.34)	24.41 (4.11)	24.59 (4.31)	F=2.62 p=.073
WtC	Nursing care	4.22 (1.02)	4.31 (0.79)	4.47 (0.62)	F=.50 p=.606	3.74 (0.99)	3.96 (1.06)	3.79 (1.06)	F=.44 p=.645	4.54 (0.59)	4.33 (0.81)	4.43 (0.72)	F=1.46 p=.235	4.38 (0.86)	4.12 (1.09)	4.11 (1.01)	F=1.74 p=.178	3.54 (0.68)	3.06 (1.02)	3.58 (0.67)	F=3.82 p=.025*	4.36 (0.67)	4.36 (0.95)	4.35 (0.73)	F=.006 p=.994	4.20 (.87)	4.03 (1.02)	4.11 (.91)	F=2.48 p=.084

	Emotional care	4.24 (1.00)	4.27 (0.68)	4.39 (0.54)	F=.22 p=.800	4.41 (0.61)	4.40 (0.61)	4.45 (0.63)	F=.04 p=.955	4.41 (0.59)	4.35 (0.67)	4.38 (0.64)	F=.19 p=.826	4.62 (0.63)	4.48 (0.73)	4.52 (0.71)	F=.70 p=.497	4.32 (0.79)	4.20 (0.80)	4.36 (0.73)	F=.37 p=.686	4.63 (0.60)	4.67 (0.33)	4.45 (0.65)	F=1.73 p=.181	4.45 (.70)	4.36 (.69)	4.38 (.69)	F=1.54 p=.213
	Instrumental care	4.42 (0.73)	4.53 (0.54)	4.56 (0.55)	F=.39 p=.676	4.31 (0.73)	4.46 (0.62)	4.30 (0.69)	F=.50 p=.603	4.63 (0.55)	4.51 (0.54)	4.43 (0.65)	F=1.78 p=.170	4.45 (0.71)	4.28 (0.82)	4.29 (0.81)	F=1.04 p=.355	3.75 (0.50)	3.62 (0.92)	3.85 (0.41)	F=1.02 p=.363	4.62 (0.45)	4.71 (0.55)	4.53 (0.57)	F=1.10 p=.336	4.43 (.67)	4.36 (.74)	4.31 (.71)	F=2.49 p=.083
	Global score	4.27 (0.86)	4.37 (0.55)	4.44 (0.48)	F=.39 p=.676	4.16 (0.67)	4.27 (0.64)	4.18 (0.69)	F=.29 p=.749	4.49 (0.50)	4.40 (0.55)	4.44 (0.52)	F=.55 p=.576	4.49 (0.66)	4.30 (0.73)	4.31 (0.75)	F=1.53 p=.218	3.87 (0.50)	3.61 (0.79)	3.93 (0.46)	F=2.47 p=.090	4.51 (0.43)	4.58 (0.56)	4.44 (0.50)	F=.71 p=.494	4.34 (.65)	4.24 (.70)	4.27 (.65)	F=1.82 p=.162
WHO-5		45.41 (24.36)	47.42 (24.33)	40.38 (22.76)	F=.53 p=.587	62.03 (21.15)	63.84 (25.51)	55.88 (20.28)	F=1.21 p=.301	41.35 (22.56)	38.58 (25.19)	41.09 (19.88)	F=.28 p=.752	53.44 (22.75)	52.00 (22.35)	51.17 (25.39)	F=.17 p=.836	46.16 (26.45)	43.48 (24.50)	42.62 (21.97)	F=.15 p=.853	45.60 (22.49)	40.32 (27.05)	40.88 (22.70)	F=.74 p=.476	48.30 (23.64)	44.48 (26.22)	44.25 (23.56)	F=3.04 p=.048 *
GAINS		10.51 (8.05)	9.92 (5.57)	11.76 (5.83)	F=.45 p=.635	8.80 (6.34)	11.00 (5.86)	12.70 (7.00)	F=4.29 p=.016 *	10.58 (6.50)	11.11 (6.07)	10.80 (6.66)	F=.11 p=.890	14.08 (6.72)	13.97 (5.42)	15.13 (6.06)	F=.65 p=.521	15.25 (4.97)	14.48 (7.08)	16.11 (6.21)	F=.56 p=.572	16.48 (6.67)	16.28 (6.71)	16.66 (6.53)	F=.03 p=.970	12.44 (6.94)	12.87 (6.53)	14.00 (6.65)	F=4.78 p=.009 **
ZBI		18.45 (9.13)	24.03 (8.62)	25.47 (9.77)	F=4.52 p=.014 *	16.90 (8.14)	16.80 (9.18)	16.17 (8.96)	F=.08 p=.919	18.79 (8.79)	21.93 (9.91)	22.23 (7.15)	F=3.12 p=.046 *	16.91 (8.80)	21.02 (9.42)	19.01 (8.70)	F=2.88 p=.058	21.66 (11.10)	24.93 (10.02)	24.51 (7.77)	F=.91 p=.405	19.81 (9.86)	23.92 (9.71)	24.85 (7.31)	F=4.89 p=.009	18.63 (9.06)	22.41 (9.92)	21.93 (8.72)	F=17.00 p=.000 ***
CES-D		10.80 (6.18)	12.60 (6.92)	13.47 (5.68)	F=1.23 p=.298	8.72 (5.79)	8.23 (6.15)	9.44 (4.97)	F=.35 p=.702	12.09 (6.40)	13.46 (7.42)	12.90 (5.90)	F=.73 p=.480	9.91 (5.71)	10.45 (5.61)	9.27 (5.55)	F=.54 p=.580	11.45 (6.53)	13.00 (6.40)	12.82 (5.80)	F=.48 p=.617	11.43 (6.42)	13.64 (7.39)	13.44 (6.76)	F=1.62 p=.201	10.83 (6.24)	12.34 (7.00)	12.13 (6.30)	F=5.42 p=.005 **
EQ-5D	Utility index	0.82 (0.12)	0.82 (0.18)	0.80 (0.19)	F=.11 p=.893	0.91 (0.10)	0.89 (0.12)	0.87 (0.09)	F=1.03 p=.359	0.72 (0.23)	0.73 (0.26)	0.68 (0.27)	F=.59 p=.553	0.78 (0.20)	0.82 (0.10)	0.75 (0.20)	F=1.66 p=.191	0.84 (0.13)	0.83 (0.12)	0.83 (0.12)	F=.06 p=.939	0.81 (0.17)	0.82 (0.14)	0.78 (0.17)	F=.59 p=.553	.81 (.18)	.80 (.20)	.77 (.20)	F=3.08 p=.046 *

The differences could not be examined in: Germany as there were 5 care recipients with neurological health condition; Ireland as there were 10 care recipients with neurological health condition; Poland as there were 15 care recipients with neurological health condition. *p < .05; **p < .01; ***p < .001

Table 11 The effect of caregiver perceived choice to assume the caring role on key study variables

	Country	**Israel**			**Italy**			**Netherlands**			**Poland**			**UK**			**Total sample**		
Scale	Caregiver choice	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value	No	Yes	t p value
	Subscale	N=82	N=43		N=134	N=53		N=158	N=31		N=46	N=23		N=103	N=36		N=712	N=234	
RFS	Total score	48.41	49.55	t=-0.54	43.05	44.67	t=-0.88	39.71	38.93	t=.39	45.10	44.13	t=.36	43.97	43.77	t=.11	42.22	44.31	t=-2.54
		(9.04)	(12.21)	p=.590	(11.04)	(12.05)	p=.379	(10.47)	(8.09)	p=.695	(9.75)	(11.65)	p=.714	(8.84)	(7.64)	p=.907	(10.87)	(11.08)	p=.011*
	Familial interconnectedness	32.37	32.95	t=-0.48	28.97	30.03	t=-0.94	27.84	27.67	t=.14	29.41	29.17	t=.15	29.20	29.08	t=.11	28.49	29.64	t=-2.32
		(5.99)	(6.88)	p=.629	(6.67)	(7.53)	p=.343	(6.37)	(5.06)	p=.888	(5.60)	(6.49)	p=.874	(5.42)	(4.61)	p=.905	(6.55)	(6.58)	p=.020*
	Family support	7.92	8.55	t=-1.31	6.73	6.64	t=.19	5.99	5.54	t=.81	7.76	7.69	t=.08	7.04	7.47	t=-0.89	6.63	7.21	t=-2.60
		(2.42)	(2.75)	p=.189	(2.95)	(3.19)	p=.843	(2.76)	(2.81)	p=.415	(2.99)	(2.96)	p=.931	(2.54)	(2.13)	p=.371	(2.93)	(3.01)	p=.009**
	Familial obligations	8.04	8.58	t=-0.93	7.73	7.37	t=.68	6.43	5.70	t=1.35	7.78	6.56	t=1.41	7.33	7.19	t=.27	7.21	7.30	t=-0.38
		(2.69)	(3.58)	p=.352	(3.11)	(3.39)	p=.495	(2.76)	(2.45)	p=.178	(3.30)	(3.48)	p=.161	(2.70)	(2.76)	p=.782	(3.01)	(3.29)	p=.703
IPQ	Illness threat	53.97	50.76	t=2.07	57.53	52.73	t=2.95	57.27	54.00	t=2.15	59.84	53.69	t=2.54	60.31	55.55	t=2.87	57.35	53.12	t=6.43
		(8.33)	(8.00)	p=.040*	(8.74)	(10.45)	p=.004**	(7.86)	(6.96)	p=.032*	(8.97)	(10.35)	p=.013*	(8.34)	(9.04)	p=.004**	(8.52)	(9.28)	p=.000***
MLQ	Presence of meaning	25.93	27.00	t=-1.07	22.50	26.03	t=-3.75	23.82	25.67	t=-1.82	22.56	25.82	t=-1.85	22.33	24.02	t=-1.31	23.46	25.39	t=-4.39
		(5.97)	(4.77)	p=.315	(6.91)	(5.30)	p=.000***	(5.25)	(4.70)	p=.069	(6.95)	(6.73)	p=.067	(6.69)	(6.40)	p=.190	(6.36)	(5.65)	p=.000***
	Search for meaning	21.89	23.27	t=-0.97	19.86	18.77	t=.88	20.10	20.19	t=-0.07	25.43	25.47	t=-0.02	17.53	17.97	t=-0.32	20.15	20.67	t=-0.95
		(7.16)	(8.33)	p=.332	(7.50)	(7.72)	p=.374	(6.12)	(6.55)	p=.939	(5.68)	(6.16)	p=.976	(6.70)	(7.32)	p=.742	(7.18)	(7.72)	p=.340
PVQ	Self-transcendence	2.28	2.04	t=1.59	2.14	2.04	t=.83	2.26	2.14	t=1.01	2.14	2.08	t=.34	2.27	1.99	t=1.83	2.20	2.11	t=1.70
		(.79)	(.73)	p=.112	(.76)	(.65)	p=.404	(.60)	(.58)	p=.313	(.57)	(.75)	p=.731	(.84)	(.62)	p=.068	(.72)	(.70)	p=.087
	Self-enhancement	3.41	3.43	t=-0.09	3.60	3.78	t=-1.05	4.04	4.48	t=-2.31	4.26	4.21	t=.19	4.25	4.52	t=-1.51	3.98	4.04	t=-0.75
		(.99)	(1.04)	p=.923	(1.02)	(1.10)	p=.294	(1.00)	(.80)	p=.021*	(.86)	(.85)	p=.843	(.88)	(.89)	p=.131	(1.02)	(1.04)	p=.449
MECS	EXMECS	28.69	22.79	t=7.08	28.89	25.71	t=3.62	27.44	22.32	t=5.23	28.45	25.69	t=2.25	28.90	25.66	t=3.73	28.41	24.62	t=9.50
		(4.15)	(4.90)	p=.000***	(4.32)	(5.76)	p=.000***	(4.83)	(5.65)	p=.000***	(3.87)	(6.26)	p=.027*	(4.46)	(4.51)	p=.000**	(4.49)	(5.52)	p=.000***
	INMECS	24.69	24.13	t=.75	24.79	25.43	t=-0.92	24.94	25.67	t=-0.79	23.23	24.39	t=-0.87	25.27	26.33	t=-1.53	24.70	25.00	t=-0.91
		(4.09)	(3.59)	p=.454	(4.09)	(4.51)	p=.354	(4.87)	(3.72)	p=.428	(4.89)	(5.67)	p=.385	(3.81)	(2.80)	p=.128	(4.33)	(4.11)	p=.361
WtC	Nursing care	3.76	3.87	t=-0.55	4.42	4.49	t=-0.58	4.18	4.51	t=-1.73	3.96	3.86	t=.44	4.33	4.41	t=-0.56	4.11	4.19	t=-1.10
		(1.07)	(.91)	p=.579	(.72)	(.69)	p=.556	(.97)	(.91)	p=.084	(.80)	(.93)	p=.654	(.77)	(.66)	p=.570	(.93)	(.90)	p=.269
	Emotional care	4.30	4.65	t=-3.62	4.33	4.51	t=-1.75	4.50	4.82	t=-4.22	4.01	4.10	t=-0.47	4.55	4.63	t=-0.71	4.37	4.51	t=-2.88
		(.67)	(.39)	p=.000***	(.65)	(.56)	p=.080	(.72)	(.26)	p=.000***	(.79)	(.75)	p=.639	(.54)	(.71)	p=.477	(.70)	(.65)	p=.004**
	Instrumental care	4.31	4.39	t=-0.68	4.54	4.54	t=-0.01	4.35	4.41	t=-0.41	4.32	4.04	t=1.51	4.57	4.68	t=-1.02	4.37	4.39	t=-0.33
		(.74)	(.58)	p=.497	(.56)	(.62)	p=.996	(.80)	(.60)	p=.680	(.68)	(.75)	p=.135	(.53)	(.48)	p=.305	(.71)	(.68)	p=.734
	Global score	4.13	4.30	t=-1.55	4.44	4.47	t=-0.33	4.36	4.58	t=-1.98	4.11	4.04	t=.41	4.48	4.54	t=-0.62	4.27	4.34	t=-1.25
		(.72)	(.53)	p=.123	(.51)	(.56)	p=.739	(.73)	(.53)	p=.051	(.61)	(.72)	p=.679	(.48)	(.49)	p=.532	(.67)	(.66)	p=.208
WHO-5		58.43	65.11	t=-1.62	37.07	48.67	t=-3.22	51.24	58.06	t=-1.47	25.47	41.21	t=-2.51	42.17	44.66	t=-0.54	43.93	52.32	t=-4.62
		(22.76)	(19.77)	p=.106	(22.13)	(22.22)	p=.001**	(23.66)	(22.57)	p=.140	(16.99)	(27.53)	p=.017*	(23.72)	(22.67)	p=.584	(24.26)	(23.49)	p=.000***
GAINS		11.14	8.74	t=1.95	11.36	9.43	t=1.87	14.03	16.48	t=-2.00	11.30	12.21	t=-0.58	17.06	14.94	t=1.67	13.39	12.05	t=2.62
		(6.70)	(6.19)	p=.053	(6.62)	(5.53)	p=.061	(6.05)	(6.96)	p=.046*	(5.88)	(6.69)	p=.563	(6.42)	(6.83)	p=.095	(6.74)	(6.75)	p=.008**
ZBI		18.24	13.72	t=2.89	22.26	17.00	t=3.78	19.43	13.32	t=3.57	25.76	17.08	t=4.13	23.92	18.47	t=3.16	22.13	16.20	t=9.23
		(8.92)	(6.89)	p=.004**	(8.48)	(8.83)	p=.000***	(8.92)	(7.48)	p=.000***	(8.29)	(8.03)	p=.000***	(8.98)	(8.62)	p=.002**	(9.19)	(8.27)	p=.000***
CES-D		9.65	7.20	t=2.60	13.79	10.16	t=3.47	10.07	8.32	t=1.59	15.04	11.65	t=1.79	13.27	10.72	t=2.29	12.23	9.85	t=4.92
		(6.06)	(4.32)	p=.010*	(6.35)	(6.64)	p=.000***	(5.51)	(6.02)	p=.112	(6.87)	(8.34)	p=.076	(7.15)	(5.14)	p=.024*	(6.41)	(6.40)	p=.000**
EQ-5D	Utility index	.88	.92	t=-2.70	.71	.72	t=-0.20	.78	.75	t=.67	.83	.85	t=-0.57	.80	.80	t=-0.17	.79	.80	t=-0.86
		(.12)	(.08)	p=.007**	(.23)	(.30)	p=.836	(.18)	(.22)	p=.501	(.15)	(.17)	p=.566	(.17)	(.16)	p=.860	(.18)	(.22)	p=.387

The differences could not be examined in: Germany as there were 9 caregivers perceiving a choice in assuming the caring role; in Greece as there were 19 caregivers perceiving a choice in assuming the caring role; In Ireland as there were 8 caregivers perceiving a choice in assuming the caring role; in Sweden as there were 12 caregivers perceiving a choice in assuming the caring role. *p < .05; **p < .01; ***p < .001

D7 Appendix - Covariates listed for each mediation and moderated mediation model

The identification of covariates was informed by previous research (e.g., caregivers' and care recipients' gender and age) and by significant associations between categorical demographic variables (e.g., living arrangements) and continuous demographic variables (e.g., Katz Index), and the mediator and outcome study variables.

The numbers of models below correspond to the number of models presented in Chapter 7.

4.1 Familism as a predictor variable

4.1.1 The mediation model for familism-motivations-caregiver wellbeing

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, intensity of care, KATZ Index.

4.1.2 The mediation model for familism-intrinsic motivations/willingness-caregiver gains

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

4.1.3 The mediation model for familism-extrinsic motivations-quality of life

The model was controlled for: caregiver's country of residence, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, care recipient's age, time spend providing care, intensity of care, KATZ Index.

4.1.4 The mediation model for familism-motivations/willingness-caregiver burden

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index

4.1.5 The mediation model for familism-extrinsic motivations/willingness-caregiver depression

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, time spend providing care, intensity of care, KATZ Index.

4.2 Self-transcendence values as a predictor variable

4.2.1 The mediation model for self-transcendence-intrinsic motivations-wellbeing

The model was controlled for: caregiver's country of residence, caregiver’s gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, intensity of care, KATZ Index.

4.2.2 The mediation model for self-transcendence-motivations/willingness-gains

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient’s age, time spend providing care, intensity of care, KATZ Index.

4.2.4 The mediation model for self-transcendence-motivations/willingness-burden

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient’s age, time spend providing care, intensity of care, KATZ Index.

4.2.5 The mediation model for self-transcendence-willingness-depression

The model was controlled for: caregiver's country of residence, caregiver’s gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, time spend providing care, intensity of care, KATZ Index.

4.3 Self-enhancement values as a predictor variable

4.3.1 The mediation model for self-enhancement values-intrinsic motivations-wellbeing

The model was controlled for: caregiver's country of residence, caregiver’s gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, intensity of care, KATZ Index.

4.3.2 The mediation model for self-enhancement values-motivations/willingness-gains

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient’s age, time spend providing care, intensity of care, KATZ Index.

4.3.4 The mediation model for self-enhancement values-motivations/willingness-burden

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient’s age, time spend providing care, intensity of care, KATZ Index.

4.3.5 The mediation model for self-enhancement values-willingness-depression

The model was controlled for: caregiver's country of residence, caregiver’s gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, time spend providing care, intensity of care, KATZ Index.

4.4 Presence of meaning as a predictor variable

4.4.1 The mediation model for presence of meaning-motivations-caregiver wellbeing

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, intensity of care, KATZ Index.

4.4.2 The mediation model for the presence of meaning-intrinsic motivations/willingness-caregiving gains

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

4.4.3 The mediation model for the presence of meaning-extrinsic motivations-quality of life

The model was controlled for: caregiver's country of residence, caregiver’s gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, time spend providing care, intensity of care, KATZ Index.

4.4.4 The mediation model for the presence of meaning-motivations/willingness-caregiver burden

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

4.4.5 The mediation model for the presence of meaning-extrinsic motivations/willingness-caregiver depression

The models were controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

4.5 Search for meaning as a predictor variable

4.5.1 The mediation model for the search for meaning-extrinsic motivations-caregiver wellbeing

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, KATZ Index.

4.5.2 The mediation model for search for meaning-willingness-caregiving gains

The model was controlled for: caregiver's country of residence, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spent providing care, KATZ Index.

4.5.3 The mediation model for the search for meaning-extrinsic motivations-quality of life

The model was controlled for: caregiver's country of residence, caregiver’s gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, time spend providing care, intensity of care, KATZ Index.

4.5.4 The mediation model for the search for meaning-motivations/willingness-caregiver burden

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

4.5.5 The mediation model for the search for meaning-extrinsic motivations/willingness-caregiver depression

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

4.6 Illness threat as a predictor variable

4.6.1 The mediation model for illness threat-extrinsic motivations-caregiver wellbeing

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, KATZ Index.

4.6.3 The mediation model for illness threat-extrinsic motivations-caregiver quality of life

The model was controlled for: caregiver's country of residence, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, time spent providing care, intensity of care, KATZ Index.

4.6.4 The mediation model for illness threat-extrinsic motivations-caregiver burden

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, intensity of care, KATZ Index.

4.6.5 The mediation model for illness threat-extrinsic motivations-caregiver depression

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, intensity of care, KATZ Index.

5. The moderated mediation analyses based on caregivers’ perception of choice in assuming the caregiving role

5.1 The moderated mediation model for familism-extrinsic motivations-burden

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

5.4.1 The moderated mediation model for the presence of meaning-extrinsic motivations-wellbeing

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, intensity of care, KATZ Index.

5.4.2 The moderated mediation model for the presence of meaning-extrinsic motivations-burden

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

5.4.3 The moderated mediation model for the presence of meaning-extrinsic motivations-depression

The model was controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, time spend providing care, intensity of care, KATZ Index.

5.6 The moderated mediation model for illness threat-extrinsic motivations

The models were controlled for: caregiver's country of residence, gender, education, employment, having support from other caregivers, caregiver's health condition, care recipient's number of health conditions, caregiver's previous care experience, caregiver-care recipient relationship type, living arrangements, care recipient's health condition type, caregiver age, care recipient's age, KATZ Index.