

Understanding informal caregivers' motivation from the perspective of self-determination theory: an integrative review

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Background: A long-term illness is stressful both for the person with the diagnosis and for his or her informal caregivers. Many people willingly assume the caregiving role, so it is important to understand why they stay in this role and how their motivation affects their health. Self-determination theory (SDT) is a theory of human motivation that has been successfully applied in human research domains. To our knowledge, there is no literature review on the application of SDT in a caregiver context. A systematic review of the literature could improve the understanding of motivation in caregiver work and contribute to the utility of SDT.

Aim: To describe and explore empirical studies of caregivers' motivation from the perspective of self-determination theory.

Methods: An integrative literature review according to Whittemore and Knafl was conducted with systematic repetitive searches in the MEDLINE, Scopus, PsychInfo, PsycNET, Chinal, Cochrane Library and EMBASE

databases. The searches were performed from May through December 2018. The PRISMA diagram was used for study selection, and papers were assessed for quality based on the Mixed Methods Appraisal Tool. Data analysis consisted of a four-stage narrative analysis method.

Result: Of 159 articles, 10 were eligible for inclusion. All studies considered satisfaction of the three basic psychological needs for competence, autonomy and relatedness as essential in predicting the quality of caregivers' motivation and thereby their well-being. In this review, autonomous motivation was the most important determinant of caregivers' well-being.

Conclusions: Findings showed that SDT can be applied to identify, categorise, explain, predict, promote and support motivation among caregivers. This lends interesting support for SDT and promotes further study and application of the theory as a psychological approach to caregivers' health and health promotion.

Keywords: informal caregiver, long-term illness, well-being, motivation, self-determination theory, integrative review.

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Introduction

Long-term serious illness such as dementia, Parkinson's, multiple sclerosis, and cancer are demanding and often debilitating conditions that affect both the care recipients themselves and their informal caregivers on several levels (1,2).

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As the illness progresses, the need for care and assistance increases for the person living with a long-term condition. Family members or other informal caregivers, either instead of or in addition to professional caregivers (3,4) attend to the person with a patient's needs. Informal caregiving consists of the ongoing activities and experiences involved in offering unpaid help to relatives or friends who are unable to take care of themselves (5,6). In Norway, informal caregivers provide approximately 50% of all care (7). Across the EU, family carers account for more than 80% of all care (4,8). Informal caregiving will continue to be essential in the light of the future demographic makeup of the population and the cost pressure on long-term care systems. Supporting and

maintaining the supply of family care appears to benefit the care recipient, the caregiver and the public system (3,4). Accordingly, the research literature recommends tailored interventions (1) and support services (9), to caregivers who are struggling to remain motivated (10).

Motivation for long-term caregiving is crucial for the way in which the informal carers experience caregiving (10). The perceived burden on the caregiver, the caregiver's approach to caring and his or her coping strategies depend on the type of illness or condition (2); family relations (11); volition in caregiving (12); and caregiver's resources (13). The present understanding of caregiving, still based on a stress-coping paradigm to reduce the burden on caregivers has become the main goal in the health services (6,14). The promotion of the positive aspects of caregiving, such as the sense of satisfaction, autonomy and expertise among caregivers as specific and legitimate goals (5,6,14,15) deserves greater attention. Many people offer informal caregiving so it is important to understand their motivation for assuming and remaining in this role (10) and these topics are not fully understood (5). Motivational processes energise behaviour, initiate, generate and increase task engagement and direct actions towards certain goals. Support for healthy motivation by important others influences a person's motivational orientations over time and shape his or her sense of well-being, psychological growth and resilience over the long-term (16). Studying motivation within a theoretical framework can illuminate the ways in which different motivations can positively or negatively influence caregivers' well-being (10).

Self-determination theory (SDT) is a broad framework that conceptualises the empirical study of human motivation (17,18). SDT identifies three innate psychological needs as a key drivers of motivation that influence well-being and thriving: autonomy, competence and relatedness. The need for *autonomy* refers not to independence but rather to volition – the sense that one's actions are endorsed by oneself, that one has a feeling of choice and ownership of his or her actions. The need for *competence* relates to the mastery and to the perception of performing a task with confidence; the need for *relatedness* is a feeling of mutual belonging and of supporting and being supported by others (17–19). Fulfilment of these basic needs promotes autonomous motivation and intrinsic aspirations, reflecting innate psychological nutrients essential for functioning, psychological health and well-being (17,18,20). SDT is particularly concerned with how social contextual factors support or thwart people's ability to thrive through the satisfaction of their basic psychological needs (18,19,21). According to SDT, motivation is not characterised by frequency or amount, like little or much motivation, but rather by a continuum from amotivation or controlled motivation to high-quality motivation distinguished by autonomous regulated behaviour

(18,22). From the perspective of SDT, a high quality of motivation predicts beneficial health outcomes like well-being, thriving and psychological growth (22).

No literature review to date on the application of SDT in a caregiver context has been identified in scientific databases or as protocols for literature reviews in Cochrane Library or Prospero, International Prospective Register of Systematic Reviews. A systematic review of literature could aid the understanding of motivation in caregiver work and might contribute to the utility of SDT. The theory has been applied in many research domains, such as education, work, sport, religion, psychotherapy, health care and behaviour change (20,23). Within these contexts, the theory has been used to identify, understand, explain, predict, promote and support individual motivation (19–21). According to the theory developers, the SDT perspective may predict the motivation of family caregivers for becoming caregivers, influencing the effect of the role on them. Preliminary evidence shows that autonomous versus controlled motivation for giving care to ill family members tends to affect the well-being and health outcomes of caregivers (18). Thus, further exploration of the role of SDT in understanding caregiving motivation is recommended.

Aim

To describe and explore empirical studies of caregivers' motivation from the perspective of self-determination theory.

Method

This integrative review was conducted as outlined by Whitemore and Knafl (24). An integrative review incorporates evidence from studies conducted using a wide variety of research methodologies (25). This approach is especially useful when the research topic may lend itself to theoretical, quantitative and qualitative methods of investigation (24). An integrative literature review is suitable when the topic has not been extensively researched (26). A preliminary literature search revealed a limited research area that consisted of diverse methodologies. Therefore, the integrative review method by Whitemore and Knafl (24) was considered as the most efficient approach. This allowed the inclusion of both qualitative and quantitative studies in order to more fully understand the research topic of caregivers motivation, and provide more solid evidence base with the potential for contributing to SDT theory development (24).

Research question and eligibility criteria

Having identified the research area of interest, the research question that guided the review process was formulated as follows:

How can an adult informal caregiver’s motivation for taking care of a friend or relative with a long-term illness be understood from the perspective of self-determination theory?

Table 1 shows the priori inclusion and exclusion criteria.

Literature search

Eligible studies were identified from database searches, a manual search of reference lists, and consultation with experts. The literature search in databases used combinations of the following search terms: ‘caregiver’, ‘family care’, ‘next of kin’, ‘informal care’ and ‘self-determination theory’. Relevant MeSH and thesaurus terms were applied when possible. The search strategy began with the union (‘OR’) of terms to capture articles related to the main concept ‘caregiver’, and then the intersection (‘AND’) of the term ‘self-determination theory’ to identify the full range of articles that combined the two main concepts. In databases that allowed limitations, peer reviewed articles were preferred, and no limitations were placed on publication year or language. The searches were done under the supervision of a specialised librarian at the University of Stavanger.

An initial systematic literature search of bibliographic databases MEDLINE, Scopus, PsychInfo, PsycNET, Chinal and Cochrane Library was conducted in May 2018, resulting in 105 titles. An updated and extended search was performed in December 2018, including the search terms ‘spouse’, ‘filial’ and ‘relatives’, and by adding the EMBASE database. The updated search identified 54 new titles, and entries for two new eligible papers were added to the annotated bibliography. The new papers tended to confirm or extend, rather than challenge, the initial synthesis. See Table 2 for an example of search strings form the database MEDLINE.

Table 1 Inclusion and exclusion criteria

Inclusion	Exclusion
Health context	Not health context
Adult informal caregivers	Children under 18 years as caregivers
Patient/person cared for must have a long-term illness	Caregiving in an acute illness setting
Informal caregiver perspective	Formal/professional caregiver perspective only
Reporting informal caregiver outcome	Studies reporting patient outcomes only
Specified use of self-determination theory	
Peer reviewed articles	Books, book chapters, protocols, reviews, study protocols, conference and poster abstracts

Study selection

A total of 159 titles were identified. After removal of duplicate items (N = 100), none of the remaining records (N = 59) were excluded after scanning of titles. Guided by the eligibility criteria (Table 1), the remaining abstracts were independently evaluated by the authors. Reasons for exclusion abstracts were mostly studies not reporting from a health context (N = 15), and studies reporting patient outcomes only (N = 19). Of the reviewed abstracts, 14 articles were selected for a full-text read. After screening the full-text records identified in the database search, eight articles were included in the review. Manual searches were performed in the reference lists of included studies and two additional studies were included. Figure 1 details and describes the identification and selection process using the PRISMA flow diagram (27).

Data evaluation

Data evaluation is crucial to enhance the rigour of an integrative review (24). The Mixed Methods Appraisal Tool (MMAT), version 2018 (28), was used to evaluate the methodological quality of the included articles. The MMAT (29) is designed for methodological quality appraisal when performing complex systematic reviews, and assesses the quality of qualitative, quantitative and/or mixed methods studies (28). For this review, checklists for qualitative, randomised and descriptive quantitative research studies were used. Rating and reporting a total score for each article is not recommended, but is rather used to give a description of study quality (30). Data evaluation was performed by all authors who independently rated the articles, followed by a discussion to achieve consensus. The quality of the included studies was above moderate, with MMAT remarks on four of them. See Table 3, spreadsheet on the MMAT for more

Table 2 Example of systematic literature search in MEDLINE, conducted December 2018

<i>Search modes - Boolean/PhraseInterface - EBSCOhost</i>		
<i>Research Databases</i>	<i>MEDLINE</i>	<i>Result</i>
S1	"self-determination theory"	1250
S2	"caregiv*" OR (MH "Caregivers")	69 488
S3	"family care"	1727
S4	"informal care"	4659
S5	"next of kin"	1292
S6	"filial*"	1383
S7	"spous*" OR (MH "Spouses")	30 055
S8	"relatives"	53 260
S9	S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8	153 830
S10	S1 AND S9	29

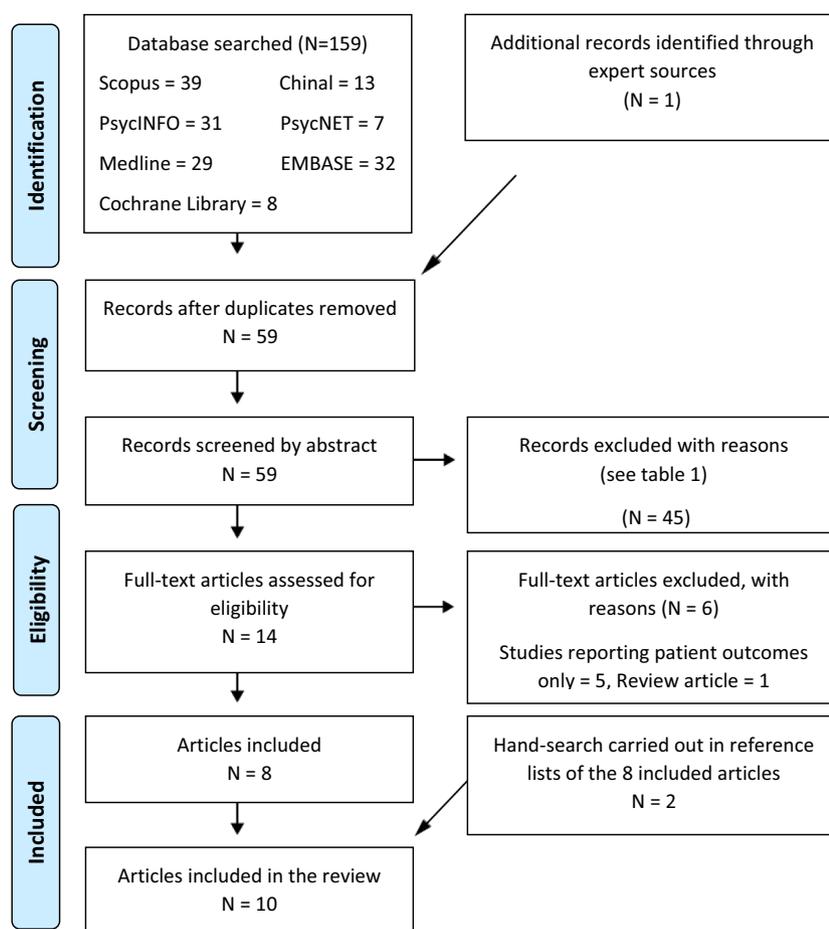


Figure 1 Paper selection strategy flow chart. PRISMA workflow of the identification, screening, eligibility and inclusion of the studies in the integrative review (27)

information. No papers were excluded based on the quality assessment.

Data analysis

The included articles are presented in Table 4, comprising information on first author, publication year, origin, study aim, study design, sample description and short summary of main findings relevant to our research question. The data analysis comprised four stages, (1) *data reduction*, (2) *data display*, (3) *data comparison* and (4) *conclusion drawing and verification* (24). The synthesis of evidence was performed as a narrative analysis allowing for a movement from descriptions of patterns and relationships to higher levels of abstraction from the particular to the general (24,26).

The data analysis was carried out during two analysis workshops in which all authors participated. In the first stage, relevant data from each article were extracted and compiled into a matrix (Table 4) (*data reduction*). In the second stage, extracted data were converted into a display to visualise patterns and relationships among the primary

sources (*data display*). The tabulation of quantitative and qualitative findings within a single matrix supported the synthesis of both statistical and narrative data, facilitating a systematic comparison of the primary data sources (24). The third stage involved coding of text by the first author and a read-through by the authors to identify new themes or data suggesting variance or dissonance within or between articles (*data comparison*). In the fourth stage, an interpretive approach was used to describe how caregivers' motivation could be understood from an SDT perspective. The data synthesis was then verified by the findings from the included articles for confirmability and accuracy (*conclusion drawing and verification*).

Results

Three themes emerged from the narrative analysis. The first theme address descriptions of caregivers' motivation. The second theme contains information on the connection between caregivers' motivation and their well-being; the third theme describes how caregivers' motivation can be supported.

Table 3 Quality appraisal of the selected studies (N = 10) spreadsheet on the Mixed Methods Appraisal Tool (MIMAT)(28)

Screening questions		Qualitative studies						Comments
Are there clear research questions?	Do the collected data allow to address the research questions?	Is the qualitative approach appropriate to answer the research question?	Are the qualitative data collection methods adequate to address the research question?	Are the findings adequately derived from the data?	Is the interpretation of results sufficiently substantiated by data?	Is there coherence between qualitative data sources, collection, analysis and interpretation?		
Ng et al., (2016)	Yes	Yes	Yes	Yes	Yes	Yes		
Strekalova, (2016)	Yes	Yes	Yes	Can't tell	Yes	Yes	Do not describe the process of analysis	
Randomised controlled trials (RCT)								
		Is randomisation appropriately performed?	Are the groups comparable at baseline?	Are there complete outcome data?	Are outcome assessors blinded to the intervention provided?	Did the participants adhere to the assigned intervention?		
Badr et al., (2015)	Yes	Yes	Yes	Yes	No	Yes	Not blinded RCT	
Cossette et al., (2016)	Yes	Yes	Yes	Yes	No	Yes	Not blinded RCT	
Quantitative descriptive studies								
		Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?		
Kim et al., (2008)	Yes	Yes	Yes	Yes	Yes	Yes		
Kim et al., (2015)	Yes	Yes	Yes	Yes	Yes	Yes		
Kindt et al., (2015)	Yes	Yes	Yes	Yes	Yes	Yes		
Kindt et al., (2016)	Yes	Yes	Yes	Yes	Yes	Yes		

Table 3 (Continued)

Quantitative descriptive studies		Is the sampling strategy relevant to address the research question?	Is the sample representative of the target population?	Are the measurements appropriate?	Is the risk of nonresponse bias low?	Is the statistical analysis appropriate to answer the research question?	
Kindt et al., (2017)	Yes	Yes	Yes	Yes	Yes	Yes	
Pierce et al., (2001)	Yes	Yes	Yes	Yes	Can't tell	No	Do not describe the analysing process

Description of caregivers' motivation

All studies included here lent insight to the situational demands that influenced adult caregivers' motivation for providing care to a friend or relative with a long-term illness. Most of the studies had investigated caregivers' quality of motivation and classified it according to different constructs in SDT such as intrinsic motivation, identified motivation, introjected motivation, external motivation (31–38) and amotivation (35). In these studies, SDT terminology has been used to identify, measure, classify, categorise or describe caregivers' quality of motivation. In several of the studies, SDT constructs were presented as categories of autonomous motivation like intrinsic motivation (i.e. helping because you enjoy/value this behaviour and experience volition and choice), or controlled motivation, understood as extrinsic motivation (i.e. helping because you believe you should) (31–37,39). One qualitative study reported that in real life, the constructs and categories of motivation are more ambiguous than, and not as easy to identify as, in the theory (37).

Two studies did not assess quality of motivation in particular, but were concerned with how caregivers could fulfil their need for autonomy, competence and relatedness (40) or the importance of internalisation where caregivers have integrated the duties and responsibilities resulting from their friend's or relative's illness (38). Pierce et al. (38) found that maintenance of motivation over time requires caregivers to internalise values and skills for caregiving and to experience self-determination. This could lead to greater identification with caregiving and could foster enthusiasm and well-being among caregivers. Several studies found that caregivers' feelings of caregiving as voluntary and that the need for autonomy was fulfilled, was especially important for high quality of motivation (31,32,34,36,38,39).

The majority of studies presented evidence for caregivers' helping motivation and the contribution to changes in their daily outcomes through the improvement of their need satisfaction and a decrease in their need frustration. Two studies explicitly concluded that the autonomous helping motivation was positively associated with the satisfaction of basic psychological needs (32,34), while most of the other studies merely implied it. Several studies found that autonomously motivated help compared with controlled motivated help, had beneficial effects on caregivers (31–37,39).

Caregivers' motivation and well-being

Most of the studies reported on outcomes for caregivers' well-being (31–38). In addition, equivalent terms like psychological well-being (32), mental health (33,37) physical health (33), life satisfaction (32), quality of life

Table 4 Characteristics of the included studies

<i>Author/year/ country</i>	<i>Aims</i>	<i>Study design</i>	<i>Setting and sample</i>	<i>Summary of findings</i>
Ng et al. (2016) Singapore	To explore the motivations and challenges facing family caregiving and to suggest a possible framework to guide culturally sensitive future work on caregivers	Qualitative Individual interviews Inductive thematic analysis	Caregivers of patients being treated for cancer N = 20 Female = 12 Male = 8 Age: 21–64 Mean age: 45 Relation: parents, spouse or other	Autonomous motivated caregivers cited learning points and reprioritised more effectively. Less autonomous caregivers reported more internal conflict and less control over their situation. Sociocultural values of family caregiving were not uniformly experienced as positive, and were burdensome for caregivers who gave care primarily for extrinsic motivations. The study's qualitative approach expands the framework of SDT
Strekalova (2016) USA	To understand how caregivers of newborns diagnosed with cystic fibrosis (CF) use online community forums to satisfy their need for competence, autonomy and Relatedness	Qualitative Conceptual-thematic analyses of the online forum discussions	106 threads with 645 responses written by parents on active CF online community forums Relation: Parents	Through online communication with parents in a similar situation, caregivers sought and received support for their autonomy (control over lifestyle changes and future planning), competence (understanding the diagnosis and recognising the health care needs) and relatedness (relate to the community of other families with same diagnosis, knowing they were not alone)
Badr et al. (2015) USA	To examine feasibility, acceptability and effects from a dyadic SDT intervention for patients with lung cancer and their informal caregivers	Quantitative randomised controlled trial (RCT)	Dyads of patients and caregivers Caregivers N = 39 Female = 27 Male = 12 Age: >35 Mean age: 51 Relation: spouse/partner or other close primary caregiver	The intervention was found feasible and acceptable by the participants, proven by a recruiting rate of 60%, and by participants' ratings of the intervention as helpful, relevant and convenient. The interventions found large decreases in participants' depression and anxiety, improved patient and caregiver competency and relatedness, and caregiver autonomous motivation, and a decrease in caregiver burden
Cossette et al. (2016) Canada	To test feasibility, acceptability and effects from a SDT-based nursing intervention for caregivers to support heart failure (HF) patients' self-care	Quantitative RCT	Dyads of HF patients and their caregivers Caregivers N = 32 Female = 23 Male = 9 Age: >18 Mean age: 64 Relation: Spouse, adult child, sibling, or significant other	The caregivers were overall satisfied with the intervention. The intervention proved acceptable in terms of content and structure, and highly appropriate to help HF self-management. Caregivers reported provision of high levels of support and feeling less amotivated in their supportive work
Kim et al. (2008) USA	To examine the prediction of caregiver well-being from the relationship qualities specified by attachment theory and from motives specified by SDT	Quantitative cross-sectional study Benefit finding in cancer caregiving experience, life satisfaction, and depressive symptoms were assessed to measure caregiver's psychological adjustment	Caregivers N = 314 to cancer survivors Female = 160 Male = 154 Age: >18 Mean age: 57 Relation: Spousal relationship	Autonomous motivation was associated with positive outcomes for caregivers, including less depression in men and increased benefit-finding in women. For both genders, attachment security related positively to autonomous motives for finding benefit in caregiving. Attachment anxiety related to introjected motives for caregiving and less life satisfaction, less well-being and more depression

Table 4 (Continued)

Author/year/ country	Aims	Study design	Setting and sample	Summary of findings
Kim et al. (2015) USA	To investigate the extent to which caregiving motives earlier in a relative's cancer pathway predict caregivers' spirituality and Quality of Life (QoL) years after	Quantitative longitudinal study Caregiving motives were measured after 2 years and spirituality and QoL (mental and physical health) were measured at 5 years postdiagnosis	Family caregivers N = 369 who were caring for cancer survivors Female = 233, Male = 136 Age: 19–90 Mean age: 55 Relation: family members and close friends	Internal reasons for caregiving were personal endorsement of caring as meaningful, important and valuable. Having a greater sense of autonomy correlated with having long-term greater spirituality and better mental health among male caregivers. Among female caregivers, having higher caregiving demands resulted in worse long-term physical health. Being peaceful predicted better mental health for both genders, and better physical health among men. Findings were fully consistent with SDT and therefore the theory was evaluated as useful when applied in the cancer caregiving context
Kindt et al. (2015) Belgium	To examine the relationship between autonomous versus controlled motivation to help in caregivers of individuals with chronic pain and caregivers' personal and relational function	Quantitative, cross-sectional study Outcomes tested among caregivers were life satisfaction, positive and negative affect, helping motivation, helping exhaustion, relationship quality, psychological distress, and need satisfaction	Sample of 48 couples, of which one partner had chronic pain Caregivers N = 48 Female = 12 Male = 36 Age: 31–67 Mean age: 54 Relation: Spouses and other definition of partners	Autonomous motives for helping among partners related positively to partners' well-being and relationship quality, and negatively to distress and helping exhaustion. Relationship-based need satisfaction in partners was positively associated with their personal well-being relational function. Controlled motivated partners gained little well-being from helping their partner with chronic pain. Applying SDT in a context of pain provided new insights into why chronic pain affected partners' outcome
Kindt et al. (2016) Belgium	To examine associations between day-to-day fluctuations in partners' type of helping motivation and several outcomes, among partners and chronic pain patient	Quantitative diary survey Outcomes tested among caregivers included daily helping motivation together, daily affect, relational conflict, and relational-based need satisfaction	Dyads of 70 where one partner had chronic pain Caregivers N = 70 Female = 17 Male = 53 Age: >18 Mean age: 55 Relation: Spouses and other definition of partners	Fluctuations in partners' daily autonomous helping motivation related positively to improvements in positive affect and decreases in negative affect, relational conflict, and helping exhaustion among partners. Providing autonomous help related to improvements in partners' daily relationship-based psychological need satisfaction The SDT-perspective proved useful and applying the theory within pain research has the potential of providing more clinically relevant directions
Kindt et al. (2017) Belgium	To examine whether perceived gratitude (i.e., received appreciation for providing support) in partners and goal conflicts in partners predicted partners' helping motivation	Quantitative diary study during 14 days For partners, daily goal conflict, perceived gratitude and helping motivation were assessed	Dyads of chronic pain patients (ICP) and partners. Caregivers N = 64 Female = 6 Male = 58 Age: >18 Mean age: 51 Relation: Spouses and other definition of partners	Caregivers provided more autonomously motivated help on days when they experienced fewer goal conflicts and perceived more gratitude from their partner. Perceived gratitude predicted an increase in caregivers' autonomous helping motivation the same day and the day after On days that partners experience a lot of interference between helping the ICP and other life goals, they felt more pressured to provide help

Table 4 (Continued)

Author/year/ country	Aims	Study design	Setting and sample	Summary of findings
Pierce et al. (2001) Canada	To further our understanding of the factors associated with the well-being of family caregivers by examining the contributions of commitment and self-determination	Quantitative interviews and questionnaire Outcomes tested were commitment, internalisation, caregivers' satisfaction with providing care and well-being	Caregivers of persons with dementia N = 50 Female = 35, Male = 15 Age: >18 Mean age: 54 Relation: spouse, siblings, adult children or other	Greater identification with caregiving generated enthusiasm, which then was a significant predictor of caregivers' general well-being. Enthusiasm stems from a more self-determined internalisation of caregiving. A more identified internalisation of their role lead caregivers to appraise difficult situations as less threatening

(37) and long-term health (37) were presented. All studies except Strekalova's (40) found that caregivers' different reasons for engaging in helping behaviour indicated why some caregivers experienced more stress and worse well-being than others. In five studies, variations in reasons for providing care were discussed as important elements in understanding caregivers' psychological well-being (32–34,37,38). Two studies explicitly presented satisfaction of the basic psychological needs for autonomy, competence and relatedness as mediators for predicting the quality of motivation and thereby psychological health and well-being among caregivers (32,34).

Common among the studies was the examination of the relationship between caregivers' controlled versus autonomous motivation to help, and the consequences for their well-being (32–37). These studies found that controlled (extrinsic) motivated reasons for providing care as feeling forced or obligated to take care, led to diminished well-being among caregivers. Kindt and colleagues (35) found that controlled-motivated caregivers gained little well-being from helping a partner with chronic pain and experienced increased exhaustion and stress. In other studies, caregivers reported more internal relational conflicts (34), negative affect (36) tensions in their relationship (34), and less control over their caregiver situation (37). Extrinsic motives for caregiving predicted greater depressive symptoms (36), less life satisfaction (32), more stress (36) and increased caregiver burden (33).

Six studies found that caregivers who were autonomously motivated to help experienced less stress and exhaustion than did those who viewed caregiving as an obligation (32–37). In Kindt et al. (34) partners who did not experience external or internal pressure, but who were committed to helping and derived enjoyment from it reported better well-being (34). Caregiving motivation was characterised as autonomous when caregivers' psychological needs for relatedness, autonomy and competence were met within the caregiving context (34–36). Satisfaction of these needs was

associated with life satisfaction, subjective vitality and positive affect among spousal caregivers (32–36). Caregivers who perceived gratitude from the patient (36) or who were enthusiastic about caregiving (38), were more willing to provide help. Autonomous motivated caregivers reported fewer depressive symptoms (32), greater spirituality and better mental health (33), greater personal growth and saw benefits in caregiving (32). Autonomous motivation led to increased happiness, positive affect, a sense of well-being, greater satisfaction with life (36,38) and better personal functioning and less exhaustion as a result of helping someone with a long-term illness (34–36).

Support of caregivers' motivation

All studies presented implications for further research and recommended finding better ways to support caregivers. Most of the studies argued for the value of mapping variation in the reasons for providing care and for considering the underlying motives of helping behaviour (32,34,36–38). Some studies pointed out that considering the reasons for providing informal care is important to identify caregivers who experience diminished well-being (32,38) and who might benefit from support services or counselling (34,38). Caregivers' helping motivation predicted (32–36,38), described (37) or supported (31,39) their health outcomes. Strekalova (40) addressed the psychological needs for competence (i.e. information and understanding the diagnosis), autonomy (i.e. making choices and planning for the future) and relatedness (i.e. contact and support from other families in a similar situation). She found that early identification of caregivers' needs may lead to better psychological coping and improved health outcomes (40). To increase caregivers' self-determination, Pierce et al. (38) suggested that healthcare professionals support caregivers by helping them see the options available to them and allowing them greater freedom of choice with respect to caregiving tasks. Findings from Kim et al. (33) suggest that

caregivers may benefit from interventions that facilitate their ability to be autonomously motivated.

Several studies concluded that the development and testing of SDT-based support services and interventions in a caregiver context might be useful for development of effective motivational support to caregivers (31–39). Only two studies had developed, tested and evaluated interventions to support motivation in caregivers. Badr et al. (31) tested an SDT intervention to improve quality of life for patients with advanced lung cancer and their family caregivers. The intervention consisted of standardised, tailored manuals on self-care, stress and coping, symptom management, communication skills, problem solving, and maintaining and enhancing relationships. In addition, dyads of patient and caregiver participated in weekly telephone counselling sessions. The intervention group reported improvements in depression and anxiety, a significant decrease in caregiver burden, and caregivers' increased autonomous motivation (31). Cossette and colleagues (39) tested an SDT-based intervention on dyads of heart failure patients and their caregivers. While the patient was hospitalised, the dyads were offered two face-to-face meetings with a project nurse; after the patient was discharged, they were offered three telephone-based meetings. The caregivers reported that they were less amotivated in their caregiver work and felt they provided better support to the patient (39). Results from the two intervention studies reported that the caregivers were generally satisfied with the interventions and found them helpful, relevant and convenient (31,39). Ng and colleagues (37) suggested that models of supporting caregiver wellness and intervention work ought to focus not just on reducing anxiety and depression, but also consider meaning and motivation as foundations for caregivers' long-term health and well-being.

Discussion

To our knowledge, this is the first review of the research literature that explores and discusses caregiving motivation from the SDT perspective. In sum, the analysis of the included articles has found that all studies considered satisfaction of the three basic psychological needs for autonomy, competence and relatedness as essential for predicting caregivers' quality of motivation and thus their well-being. The review holds the potential to form an important foundation for future research, and for the development of interventions that will increase caregivers' sense of self-determination.

Caregivers' motivation and well-being in a long-term illness context

The most significant finding was that fulfilment of caregivers' psychological needs and autonomous

motivation was strongly associated with their greater well-being. Our findings are consistent with Milyavskaya and Koestner (23) who found that need satisfaction is universally linked to motivation and well-being across important life domains. Other researchers have come to the same conclusion in workplace studies (19,22), among patient populations in health care, and in health promotion contexts (20). Moreover, Weinstein and Ryan (21) found that intrinsic motivation for helping yielded benefits for the helper through greater need satisfaction. Perception of choice in entering the caregiver role is positively associated with well-being among caregivers, and internalised values about the importance of caregiving are essential (12). This is consistent with our findings, where the maintenance of motivation over time requires that caregiver's internalise certain values, duties, responsibilities and skills. Moreover, this review suggests that the feelings of caregiving as voluntary and fulfilment of the need for autonomy is especially important for high-quality motivation. Also, caregivers' perception of support for their autonomy from family and friends, from their workplace and from health professionals may be associated with less depression and increased well-being and life satisfaction. In line with this, high-quality motivation is a central marker of well-being and associated with high performance (22) and personal growth (20,21). In extension of this, we see the need for health professionals supporting the caregivers' volunteering behaviour and offering guidance towards caregiving solutions to support sense of autonomy.

Our findings support the theoretical proposition that fulfilment of the basic needs for autonomy, competence and relatedness is a primary form of psychological nurturance that facilitates well-being (17,18) in caregivers. Intrinsic motivation is distinguished by autonomous motivation and self-determined behaviour where the person acts out of interest, engagement and enjoy the activity (18,20). The review show that fulfilment of the three basic psychological needs for autonomy, competence and relatedness are important determinants of caregivers' well-being, protecting them from high levels of psychological distress associated with ill-being and caregiver burden. In a job satisfaction context, amotivation, where the motivational quality is lowest and the employee finds no value or interest in acting, is associated with poor well-being and performance (19,22). The employee appears to have no self-determination and the motivation for acting is controlled, resulting in poorer well-being (17). Our narrative analyses confirmed this by showing that caregivers who reported feeling forced or obligated to offer care were extrinsically motivated or amotivated, which predicted more depressive symptoms, less life satisfaction, and greater stress and caregiver burden.

Targeting caregivers' autonomous motivation

We found that a motivational perspective on helping, as provided by SDT, is useful in explaining variations in personal and relational well-being and distress among caregivers. Early identification of caregivers who are struggling or at risk of struggling is crucial (4). It is important to identify this subgroup of caregivers so that they can receive evidence-based services (6). SDT constructs can identify, clarify and explain why caregivers in apparently similar situations differ in terms of well-being and in their desire to continue offering care. According to Roth et al. (6) it is important to target evidence-based services to the subgroup of caregivers who are under stress or at risk in other ways (6). In line with this, we found that by identifying caregivers who were intrinsically motivated or amotivated and suffering from the caregiver experience, health professionals might better understand why certain caregivers experience worse well-being than others, and how these caregivers will benefit from receiving support services or counselling.

Our results highlight the need for improved ways of supporting caregivers' motivation. Moreover, it is crucial for health professionals to understand when the provision of caregiver support is considered helpful and beneficial for the caregivers' well-being. According to previous caregiver research, health services ought to see informal carers as no less important than the patient (2,4,11). Different kinds of caregivers need different kinds of support and interventions based on, that is, types or severity of the relatives' long-term illness (1,9). Support and services to caregivers are indispensable to caregivers' psychological well-being by preventing burnout (4,8). This is consistent with our findings that well-being is facilitated by perceived support, especially support for autonomy from health professionals, the patient and from others. Given the critical role of autonomous helping motivation, health professionals can meet caregivers' needs by being autonomous supportive. Promising result from the two pilot interventions in the fields of cancer and heart failure encourage further development and testing of interventions that support caregivers. The interventions recommend that health professionals reinforce caregivers' autonomous motivation by offering choices rather than restrictions, showing the range of options available to them, avoiding criticism and giving encouragement (31,39). Accordingly, health providers should view caregivers as partners (5), and take into account caregivers' resources (13). Here, a more balanced image of the caregiver as a resilient and capable ally is useful (6). Health professionals could work more effectively and systematically with patients to identify, inform and collaborate with their informal caregivers (6). According to Quinn et al. (10) efficacious interventions should be developed

and implemented to support caregivers' motivation and thus their well-being.

Future directions for SDT in the caregiver context

Our findings suggest that models of understanding caregiver well-being ought to focus not just on the absence of stress and caregiver burden, but also consider motivation as the foundation for caregivers' long-term health and well-being. These findings meet previous research calls for promotion of benefits of caregiving, such as sense of satisfaction, autonomy and expertise among caregivers that may act as specific and legitimate goals for motivational support (5,6,14,15). The existing dominance of a stress-coping approach pathologies caregiving (6,14). In contrast, SDT represents greater attention to health promotion (20) and offers a promising theoretical framework for future research, by shifting the focus from health threat to health resources in the caregiving context.

All of the included articles described how SDT was applied in their respective studies, depicting SDT as an effective framework for understanding caregivers' motivation. In this context, it would be valuable to know more about the application of SDT in research on caregiving, and in particular, qualitative research is warranted to identify the SDT constructs' application in real life. Moreover, all of the reviewed articles included both male and female caregivers, while only two studied SDT constructs with respect to gender (32,33). The gender issue in current SDT research has provided inconsistent findings (41) representing a knowledge gap in the SDT research on caregiver motivation.

Most of the studies included in this review used SDT measurements and questionnaires validated in or adapted from other contexts. Accordingly, the development, testing and validation of SDT-based instruments and questionnaires in different languages adapted to a caregiver context are warranted. Further development of qualitative research approaches to identify methods of promoting caregivers' autonomous motivation is recommended. This could add value to a field of SDT research that is already dominated by quantitative methods. Future SDT research on caregivers should endorse reporting and reflecting on the application of SDT.

Methodological considerations

It can be methodologically challenging to include mixed evidence within one literature review. The integrative review method has been successfully adapted to allow diverse primary sources and multiple perspectives to be combined, to gain in-depth understanding of complex phenomena (26). Whittemore and Knaf's integrative

review method (24) provided a stringent approach to the current review study, represented by its rigorous and systematic review procedure.

Our search strategy was comprehensive, comprising two searches (initial and follow-up) in seven multidisciplinary bibliographical databases. This allowed for an updated and interprofessional approach to the literature search. Even though no limitations on year or language were added to the literature search, only 159 articles were found, most of them published since 2015 and published in English. This indicates a circumscribed research area, but at the same time the combination of caregiving and SDT seems new and upcoming in both research and practice. Despite a comprehensive literature search, the inclusion of grey literature might have given expanded access to the research area. To enhance the rigor of our review, a priori and well-defined selection criteria were used. All authors participated in study selection, ensuring that the identified documents were eligible for inclusion. Choosing a single motivational theory (SDT) as a theoretical perspective might be considered a strength of this review, but may have narrowed the knowledge base. The inclusion of other motivational theories might have contributed to a broader view on caregiving motivation.

Conclusions

This integrative literature review found that SDT can be applied to identify, categorise, explain, predict, promote and support motivation among caregivers. The findings are an initial demonstration of the differential effects of caregivers' autonomous versus controlled motivation for helping a friend or relative with a long-term illness. Autonomous motivation is demonstrated as an important determinant of caregivers' well-being and may protect them from feeling overstressed and overworked. When

caregivers voluntarily offer their help, they experience a greater sense of autonomy, relatedness and competence; and need satisfactions that in turn appear to enhance caregivers' sense of well-being. This review gives important support for SDT and promotes further study and application of the theory as a psychological approach to health and health promotion in the caregiver context. The further development and implementation of autonomy-supportive interventions and services to caregivers as the target group are endorsed. For future SDT research in the caregiver context, more reporting and reflection on the application of SDT are recommended. Furthermore, contributing a fresh theoretical perspective to a familiar field is a strong argument for applying SDT to the caregiver context in future research and practice.

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Conflicts of interest

The authors state explicitly that there are no conflicts of interest in connection with this article.

Author contribution

HD is the main author and takes responsibility for the content of this article. Data collection and analysis were guided by AN and AMLH. All authors critically revised the manuscript. This study is a part of a PhD thesis for which AN is a supervisor.

References

- 1 Fu F, Zhao H, Tong F, Chi Iris. A systematic review of psychosocial interventions to cancer caregivers. *Front Psychol* 2017; 8: 834.
- 2 Sullivan AB, Miller D. Who is taking care of the caregiver? *J Patient Exp* 2015; 2(1): 7–12.
- 3 Colombo F, Llena-Nozal A, Mercier J, Tjadens F. Help Wanted? Providing and Paying for Long-Term Care 2011. Available from: <https://www.oecd-ilibrary.org/content/publication/9789264097759-en>.
- 4 Zigante V. Informal care in Europe, Exploring Formalisation, Availability and Quality. European Commission, Directorate-General for Employment, Social Affairs and Inclusion Directorate A — Employment and Social Governance. 2018.
- 5 Nolan M, Grant G, Keady J. *Partnerships in Family Care*. 2003, McGraw-Hill Education, Berkshire, Great Britain.
- 6 Roth D, Fredman L, Haley W. Informal caregiving and its impact on health: a reappraisal from population-based studies. *Gerontologist* 2015; 55(2): 309–19.
- 7 Norwegian Ministry of Health- and Care Services. Helse- og omsorgsdepartementet. Meld. St. 15 (2017–2018) Leve hele livet — En kvalitetsreform for eldre. (Report no.15 (2017-2018) To live the whole life, a quality reform for people of old age). Retrieved from <https://www.regjeringen.no/no/dokumenter/meld.-st.-15-20172018/id2599850/>
- 8 Hoffmann F, Rodrigues R. *Informal Carers: Who Takes Care of Them?*. 2010, European Centre for Social Welfare Policy and Research, Vienna.
- 9 Brimblecombe N, Fernández J-L, Knapp M, Rehill A, Wittenberg R. Review of the international evidence on support for unpaid carers. London School of Economics and Political Science (LSE). 2018.

- 10 Quinn C, Clare L, Woods RT. The impact of motivations and meanings on the wellbeing of caregivers of people with dementia: a systematic review. *Int Psychogeriatr* 2010; 22(1): 43–55.
- 11 Hanssen H, Sommerseth R. Den familiære relasjonens betydning for pårørendes behov i møte med helsetjenesten. (The Significance of Family relations to Informal Carers' Needs in interaction with Health Services). *Nordisk Tidsskrift Helseforskning*. 2014; 10(2): 62–75.
- 12 Al-Janabi H, Carmichael F, Oyebode J. Informal care: choice or constraint? *Scand J Caring Sci* 2018; 32(1): 157–67.
- 13 Wennerberg M, Eriksson M, Danielsson E, Lundgren S. Unravelling Swedish informal caregivers' generalised resistance resources. *Scand J Caring Sci* 2016; 30(3): 602–13.
- 14 Brown RM, Brown SL. Informal caregiving: a reappraisal of effects on caregivers. *Soc Issues Policy Rev* 2014; 8(1): 74–102.
- 15 Yu DSF, Cheng S-T, Wang J. Unravelling positive aspects of caregiving in dementia: An integrative review of research literature. *Int J Nurs Stud*. 2018; 79: 1–26.
- 16 Weinstein N, DeHaan CR. On the Mutuality of Human Motivation and Relationships. In: *Human Motivation and Interpersonal Relationships: Theory, Research, and Applications*. (Weinstein N, ed), 2014, Springer, Dordrecht, Netherlands, 3–25.
- 17 Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *Am Psychol* 2000; 55(1): 68–78.
- 18 Ryan RM, Deci EL. *Self-determination theory: basic psychological needs in motivation, development, and wellness*. 2017, Guilford Press, New York.
- 19 Williams G, Halvari H, Niemiec CP, Sørø Ø, Olafsen A, Westbye C. Managerial support for basic psychological needs, somatic symptom burden and work-related correlates: A self-determination theory perspective. *Work Stress* 2014; 28(4): 1–16.
- 20 Ng J, Ntoumanis N, Thøgersen-Ntoumani C, Deci E, Ryan R, Duda J, et al. Self-determination theory applied to health contexts: a meta-analysis. *Psychol Health*. 2012; 27: 325–49.
- 21 Weinstein N, Ryan RM. When helping helps: Autonomous motivation for prosocial behavior and its influence on well-being for the helper and recipient. *J Pers Soc Psychol* 2010; 98(2): 222–44.
- 22 Rigby CS, Ryan RM. Self-determination theory in human resource development: new directions and practical considerations. *Adv Develop Human Res* 2018; 20(2): 133–47.
- 23 Milyavskaya M, Koestner R. Psychological needs, motivation, and well-being: a test of self-determination theory across multiple domains. *Pers Individ Differ* 2011; 50(3): 387–91.
- 24 Whittmore R, Knafk K. The integrative review: updated methodology. *J Adv Nurs* 2005; 52(5): 546–53.
- 25 Doolen J. Meta-analysis, systematic, and integrative reviews: an overview. *Clin Simul Nurs* 2017; 13(1): 28–30.
- 26 Whittmore R, Chao A, Jang M, Minges KE, Park C. Methods for knowledge synthesis: an overview. *Heart Lung* 2014; 43(5): 453–61.
- 27 Moher D, Liberati A, Tetzlaff J, Altman Douglas G. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLoS Med* 2009; 6(7): e1000097.
- 28 Hong QN, Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, et al. The Mixed Methods Appraisal Tool (MMAT) version 2018 for information professionals and researchers. *Educ Inform* 2018; 34(4): 285–91.
- 29 Pluye P, Gagnon M-P, Griffiths F, Johnson-Lafleur J. A scoring system for appraising mixed methods research, and concomitantly appraising qualitative, quantitative and mixed methods primary studies in Mixed Studies Reviews. *Int J Nurs Stud* 2009; 46(4): 529–46.
- 30 Hong QN, Pluye P, Fàbregues S, Bartlett G, Boardman F, Cargo M. Mixed Methods Appraisal Tool (MMAT), version 2018, User guide. 2018. Available from: <http://mixedmethodsappraisaltoolpublic.pbworks.com/w/page/24607821/FrontPage>
- 31 Badr H, Smith CB, Goldstein NE, Gomez JE, Redd WH. Dyadic psychosocial intervention for advanced lung cancer patients and their family caregivers: results of a randomized pilot trial. *Cancer* 2015; 121(1): 150–8.
- 32 Kim Y, Carver CS, Deci EL, Kasser T. Adult attachment and psychological well-being in cancer caregivers: the mediational role of spouses' motives for caregiving. *Health Psychol*. 2008; 27(2 SUPPL. 2): S144–54.
- 33 Kim Y, Carver C, Cannady R. Caregiving motivation predicts long-term spirituality and quality of life of the caregivers. *Ann Behav Med*. 2015; 49(4): 500–9.
- 34 Kindt S, Vansteenkiste M, Loeys T, Goubert L. Helping motivation and well-being of chronic pain couples. *Pain* 2016; 157(7): 1551–62.
- 35 Kindt S, Vansteenkiste M, Loeys T, Cano A, Lauwerier E, Verhofstadt LL, et al. When is helping your partner with chronic pain a burden? The relation between helping motivation and personal and relational functioning. *Pain Med*. 2015; 16(9): 1732–44.
- 36 Kindt S, Vansteenkiste M, Cano A, Goubert L. When is your partner willing to help you? The role of daily goal conflict and perceived gratitude. *Motivat Emot* 2017; 41(6): 671–82.
- 37 Ng HY, Griva K, Lim HA, Tan JY, Mahendran R. The burden of filial piety: a qualitative study on caregiving motivations amongst family caregivers of patients with cancer in Singapore. *Psychol Health*. 2016; 31(11): 1293–310.
- 38 Pierce T, Lydon JE, Yang S. Enthusiasm and moral commitment: what sustains family caregivers of those with dementia. *Basic Appl Soc Psychol* 2001; 23(1): 29–41.
- 39 Cossette S, Belaid H, Heppell S, Mailhot T, Guertin M-C. Feasibility and acceptability of a nursing intervention with family caregiver on self-care among heart failure patients: a randomized pilot trial. *Pilot Feasibility Stud* 2016; 2(1): 34.
- 40 Strelakova YA. Finding motivation: online information seeking following newborn screening for cystic fibrosis. *Qual Health Res* 2016; 26(9): 1180–90.
- 41 Guérin E, Bales E, Sweet S, Fortier M. A meta-analysis of the influence of gender on self-determination theory's motivational regulations for physical activity. *Can Psychol* 2012; 53(4): 291–300.