Scoping review of facilitative aspects of occupational, personal and environmental factors of caregivers occupational performance when caring for a person with major neurocognitive disorder (NCD)

Paula Tuomi

Thesis, 15 credits, one-year master of Occupational Therapy
Jönköping 5.2.2019

Supervisor : Sofi Fristeds, PhD
Examiner : Dido Green, PhD
Abstract

People with neurocognitive disorders (NCD) condition called dementia are mainly taken care by family members. The number of people suffering from neurocognitive disorders is estimated to increase. Providing care for the person with NCD can be stressful and demanding which is why effective interventions to support caregivers are needed. Occupational therapy practitioners have unique knowledge of the person, environment and occupation and how those factors influence on individuals occupational performance. Occupational therapy’s interventions to support caregivers with NCD have mainly concentrated on problems in the behaviour of person with NCD. The aim of this scoping review was to identify why some caregivers are managing better as a caregiver before any interventions have been done. What are those aspects of Person (P), Occupation (O) and Environment (E) that facilitate occupational performance (OP) when taking care for a person with NCD. PEO-model by Law et. al (Law et al., 1996) was utilized to formulate research question, in search words and in summarizing the results. The search from Ageline, Cinahl, Psycinfo and PubMed databases was done in January 2018 and went back 10 years. Results found 23 relevant articles for inclusion in the scoping review. Facilitating factors emphasized the supports of relationship seen as an overlap of caregivers and individuals with NCD on occupational performance. Facilitating personal factors of resilience, finding gains in caregiving, self-efficacy and religiosity were found to have an impact on care that the caregiver provides. Facilitative aspects of occupations highlighted importance of daily occupations as a source of well-being for both caregiver and person with NCD. In conclusion, facilitating aspects of relationships, personal factors and engagement in activities and hobbies supported occupational performance of both the caregiver and a person with NCD. Taking these factors into consideration could help target interventions more precisely to meet caregivers needs.

Keywords: facilitate, caregiver, major neurocognitive disorder, NCD, dementia, occupational performance, PEO-model, occupation, environment, personal causation
Introduction

There are about 47 million people worldwide that have dementia or major neurocognitive disorder (NCD). It is estimated that by the year 2030 the number will be 75 million and by the year 2050 as high as 135.5 million people. The costs of NCD are huge and there is no cure for the underlying disease[2]. Persons with dementia or major neurocognitive disorder (NCD) are living with their families and majority of care is often provided by family caregivers[2]. The condition, formally named dementia, is now incorporated into NCD includes e.g., vascular dementia, Alzheimer’s disease, dementia with Lewy bodies, frontotemporal dementia [3] and the term NCD will be used in this review. The symptoms these people suffer are many, such as loss of memory, changes in behaviour, problems with communication and language, aggression, apathy, depression, anxiety, difficulties of perception and hallucinations and aggression. Symptoms that NCD causes could be understood by seeing beyond the behaviour to the possible reasons in biological, psychological or social factors. The behaviour of the person may be influenced by NCD in a way, that they are unable to operate to meet the requirements of physical and social environments. Symptoms that NCD causes are often confusing to caregivers because the person behaves differently than before[4].

A growing number of people and families facing NCD points to the need for discover of effective health care interventions to support these people. Occupational therapy practitioners have unique knowledge of the person, environment and occupation to support both the persons with NCD and their caregivers [5]. The need for more research about the role of occupational therapy supporting family caregivers has been identified [6, 7]. It has been recognised in research that providing care for a person with NCD is demanding and stressful, and it has a negative influence on caregiver’s health and well-being [3, 8, 9].

In a recent systematic review evidence was found that occupation based interventions will support the caregivers of people with NCD [10]. Occupation based and occupational therapy interventions and approaches for caregivers of NCD are mainly concentrating on reducing or compensating for challenging aspects of caregiving [11, 12, 13, 14, 15, 16]. Clinical evidence is still limited regarding the effectiveness of these interventions and approaches [10, 16, 17, 18]. In research literature most of the experimental studies of caregiving for older adults have been focusing on caregivers’ burden and depression [19, 20].
The Person-Environment-Occupation Model of Occupational Performance (PEO) by Law et.al. [1]. Model was used when constructing the research question. The PEO-model conceptualizes dynamic interaction between person, environment and occupation resulting in occupational performance. A person is defined to be a unique being with dynamic and varying roles; the combination of mind, body and spiritual qualities. The Environment is defined to include cultural, socio-economic, institutional, physical and social aspects. Occupation in this model consists of the concepts of activity, task, and occupation. Activity is defined as the basic unit of the task. Task is defined as a set of purposeful activities. Occupation is defined as a group of self-directed, functional tasks and activities. Occupational performance is defined as the outcome of the interaction between the person, environment and occupation, and it is the dynamic experience by person engaging in activities and tasks [1]. The fit between person, environment and occupation is crucial in the PEO-model [21]. PEO-model is a tool that is bridging theory and practice in a simple and useful way [22]. Facilitative aspects are described to be aspects that are helpful; those which enable, motivate, support, improve or are found as gains.

Because research of occupational therapy supporting caregivers of NCD is limited and evidence that has been found has not been translated effectively into practice this study was performed. The aim of this study was to investigate aspects that facilitate caregiving and how acting as the caregiver for a person with NCD affects the caregiver's occupational performance.

The questions for the review were “What personal factors among caregiver facilitate occupational performance when caring for a family member diagnosed with dementia? What environmental facilitators support occupational performance when caring for a family member diagnosed with dementia? What occupational facilitators support occupational performance when caring for a family member diagnosed with dementia?”
**Materials and methods**

**Design**

A scoping review was undertaken to answer the research questions. Scoping reviews offer an overview of the existing research do not take the quality of the research into consideration. Scoping reviews are useful when there is need to map the key concepts of the aim rather than answer an exact question(s). Scoping reviews are also used to examine emerging evidence to be able to apply more precise questions of the research aim later. Many types of research data can be used which is also one reason to use scoping review as a research method. This scoping review was guided by the methodology for Joanna Briggs Institute’s scoping reviews. It offers a systematic approach to the conduct and report of the findings of the review and allows transparency of the research process with guidance providing instructions for every step for the research process [23]. The criteria of at least two reviewers was not possible when doing this thesis. Scoping reviews were designed to be able to more effectively synthesise the evidence to support decision making in social-and health care[23].

Inclusion criteria of the participants were that they are caregivers of persons with NCD. Context of the facilitative aspects meant factors that were supporting or helping caregiving of person with NCD before any interventions were offered. Exclusion criteria were: articles only investigating interventions or assessments, articles not dealing with caregiving, articles not dealing with people with NCD, articles not dealing with common facilitating aspects.

From 1522 articles the first exclusion was done by reading the headings and abstracts. After reading headings and abstracts 75 articles were included and after removing duplicates (26) there were 49 articles left. Articles that focussed on specific ethnic groups or were dealing with certain healthcare system of the researched country or certain situation were left out because aim was to find facilitate aspects that are common phenomenon when caregiving a person with NCD. There were 31 articles left. When reading full text seven articles were excluded, two were irrelevant from examining specific interventions and five were not dealing with facilitating aspects of caregiving. Thus, the number of studies accepted for inclusion in the scoping review were 24. (See Figure 1)
Data abstraction and synthesis

24 articles had been read by author and findings were summarised by copy pasting main points of the research to documents of their own. Shortened findings of the chosen studies were read again to be able to found main themes. Narrative extraction of the main themes was then documented and categorised under the PEO model. Then the data was summarized and gathered into one table. From the 24 articles that included in the study the characteristics and findings were gathered in table including information on: authors; publication year, title and journal, subject and country, purpose of the study, participants of the study, method (data collection and analysis); limitations of the study; results and conclusion of the review; and PEO coding. Narrative extraction of data was undertaken following the PEO model.

Results

The main points of the study are illustrated in Table 1. From the 24 studies included, three were systematic reviews, eight were based on different types of qualitative research, four included mixed-method research, five used cross-sectional design, and three quantitative research and finally one was a Delphi Consensus study (See Table 1). Systematic reviews were checked to avoid having same articles in this study. The reviews included studies from following countries: Australia, Canada, Cyprus, Hong Kong, Singapore, India, Spain, Sweden, South Africa, the UK, the USA and one study was international: including Netherlands and UK. The findings from the included articles are presented under the respective research questions to gain more understanding of the aim of this study. Person Environment Occupation-model by Law et. al was utilized to find out which areas of facilitative aspects were highlighted [1].

Facilitating personal aspects (composite of mind, body and spiritual qualities roles and skills) when taking care of a person with NCD

In thematic analysis using diary recordings by Cheng, Mak, Lau, Ng and Lam [24] ten themes related to positive gains in caregiving were found. Positive gains were described to be benefits or rewards from caregiving experiences. Gains can be intrinsic like the sense of satisfaction or extrinsic for example getting appreciation from the care receiver. Accepting of the disease was found to be the basis for several key aspects of gains. Caregivers who have
found meaning in caregiving had achieved increased amount of patience and tolerance and had learned to 'let go'. Caregivers found sense of purpose, feelings of gratification and gratitude in their caregiving role. A positive mindset was found to increase the sense of mastery in caregiving [24].
In a study of gains in caregiving by Netto, Jenny and Philip personal growth, like being more knowledgeable, resilient, patient and understanding, were considered to be the most common gains. Higher-levels of gains in caregiving were identified to be spirituality, deepened connection to God and having a more bright perspective on life in general [25]. Combination of a high sense of spirituality and self-efficacy had additive effect on caregiver’s well-being that were examined in the cross-sectional study of Lopez, Romero-Moreno, Marquez-González and Losada [26]. Grover, Nehra, Malhotra and Kate examined the positive experience of caregiving in their quantitative study with aspects such as self-esteem and finding gains in caregiving found to increase motivation on caregiving [27].

Spirituality and self-efficacy by caregivers were also researched by four groups. Caregivers with high self-efficacy and high spirituality had less depression than other groups in a cross-sectional study by Lopez, Romero-Moreno, Marques-Gonzales and Losada [26]. Nagpal, Heidb, Zarita and Whitlatche [28] researched religiosity in a quantitative study and found that more religious caregivers were assumed to have positive influence to person with NCD through their actions and communication. Caregivers with high religiosity predicted higher self-reported of quality of life (QoL) of person with NCD [28]. These authors also found that religiosity as a coping mechanism affected the quality of life of both in a dyad as well to persons with NCD self-perception[28]. In a study about gains by Netto, Jenny and Philip higher-levels of gains in caregiving were identified to be spirituality, deepened connection to God and as more bright perspective on life in general [25]. Combination of high sense of spirituality and self-efficacy had additive effect on caregiver’s well-being that were examined in the cross-sectional study of Lopez Romero-Moreno, Marquez-González and Losada [26].

In a study by Shim, Barroso, Gilliss and Davis positive meanings of caregiving were examined. Caregivers with altruistic values had found meaning to caregiving by believing in a choice of attitude and living due to their values[29]. Carers self-efficacy was found to have a positive effect on carers QoL in systematic review by Farina et. al. [30]. Contador, Fernández-Calvo, Palenzuela, Miguéis and Ramos [31] investigated predictors of burden based on Multidimensional Approach Of Optimism Model by Palenzuela in their qualitative study. They found that people with grounded optimism, self-efficacy and contingency were less vulnerable for burden and negative impact of caring [31].
Papastavrou and colleagues [31] examined associations between burden, coping and well-being of caregivers of a person with NCD in their cross-sectional study. Positive coping was negatively associated with burden and wishful thinking strategies were positively related to problem solving [31]. In a quantitative study by Grover, Nehra, Malhotra and Kate higher use of avoidance coping was associated with better motivation in a role of caregiving as well satisfaction in caregiving was associated with better quality of life [27]. In a study by Joling et. al encouragement to use positive strategies like sense of competence in caregiving was associated with the experience of gain in caregiving [33]. Caregivers feeling of competence when caregiving and sense of continuity in life were moments of well-being to them by Hasselkus and Murray[34].

The concept of resilience describes individuals who have better outcomes than others who have experienced the same level of adversity [33]. Essential features of resilience were examined by Joling, et. al. in their Delphi consensus study[33]. Less problems in behaviour of person with NCD and feeling competent as a caregiver were selected to be the most essential features of resilience by both professionals and caregivers. Experiencing caregiving as a positive thing was considered to be an essential feature of resilience by professionals opinion. Professionals regarded also coping skills of caregivers to be essential feature of resilience [33]. Resilience was also examined by Donnellan, Bennett and Soulsby [35] by interviewing spousal caregivers. The findings of their study characterised a resilient carer to be positive and knowable person who maintain relationship and loved person with NCD[35]. In a study by Papastavrou et. al. association between burden, coping and well-being in caregivers’ data suggested that improvement in the skills like coping techniques may lead to better resilience[32].

Peacock, et al [36] examined how strength-based perspective could reveal opportunities in caregiving a person with NCD. Seen by that perspective caregivers could view their role as a caregiver as an opportunity to give back, discover inner strengths, feel sense of competence and become closer to care receiver[36].

Family caregivers’ patterns of negative and positive effects were researched by Robertson, Zarit, Duncan, Rovine and Femia in their cross-sectional study [37] Four groups were discovered: Well-adjusted, Ambiguous, Intense and Distressed groups. The‘ well-adjusted’
group had best overall health and good education, reporting the highest level of competence in caregiving. The ‘ambiguous’ group reported the lowest and the ‘intense’ group the highest rewards on caregiving [37].

Corcoran [38] examined the impact of the culture of caregiving a person with NCD. Four different caregiving styles were identified. A facilitating style was cooperative, calming down and optimizing the emotional health of person with NCD. A balancing style was searching balance between dyad. An advocating style was typically aware of problems in well-being of person with NCD. In a directing style the focus was on physical health and in nutrition, hygiene and medication [38].

In the research of resilience and transitions by Gaugler, Kane and Newcomer, high baseline resilience of the caregiver was associated with less frequent placement for institutions of a person with NCD [43].

Facilitating aspects of environment (cultural, socio-economic, institutional, physical and social) when taking care a person with NCD

In a systematic review by Farina et. al [30] relationship quality between carer and person with NCD was found to have an effect on QoL of carers. The importance of relationship emerged from quantitative literature and predominant factors like relation type were found to have effect on QoL of caregiver. Results were mixed with respect to how the relationship type (spouse, child ext.) or gender effected caregivers QoL. Demographics, and more specifically, a carer living together with a person with NCD, had poorer QOL compared to those not living together with the person having NCD [43]. In a systematic review by Quinn, Clare and Woods the current relationship and relationship before NCD and the level of behaviour problems were found to have an impact on the quality of relationship between dyads [40]. Relationships were found also to have an influence on the care that caregiver provide by Farina et. al investigating factors associated with quality of life [30].

In a systematic review of Ablitt, Jonesc and Muersc [39] qualities of relationship like intimacy, reciprocity, communication, happiness in marriage and overall perceived quality of the
relationship were found to have an impact into the experience of living with NCD. Based on the results an integrative theoretical framework was proposed by the authors describing different groups of relationship [39]. Firstly, in the Continuity group companionship by both of the dyad was experienced with high level of mutuality; Secondly, in the Reciprocation group, the carer found person with NCD changed but mutuality was still experienced; Thirdly, in Detachment groups, carers perceived the person with NCD entirely changed from former self and interaction was not mutual which caused experiences with mixed feelings; and Finally, in the Duty group relationship was experienced weak and there was only little or none mutuality between dyad. Carer’s feelings were mixed about their role as a carer [39].

In a Delphi consensus study by Joling et al. [33] good quality of relationship with caregiver and person with NCD was considered to be the most important outcome of positive caregiving and the most important source of resilience [33]. Daley, O’Connor, Shrink and Beard [41] researched relationships in a mixed methods study between spousal dyads interpreting interviews based on Kaplan’s study of dyads approaches (I/Me or We/Us) In Kaplan typology of couple-hood “We” and “I” are acting as opposite poles. Couples with We/Us approach were finding more positive aspects with higher rates of positive emotions and gains related to caregiving than couples with I/Me approach concluding that the We/Us approach may be protective when caregiving [41].

In a 3-year exploratory study by Holst and Edberg [42] of persons with NCD, the state of mind and dependency were related to relationship quality. Less dependency was related to better relationship quality [42]. The connection and mutuality of relationship was found to be contributing to the well-being of both caregiver and person with NCD in everyday occupations in a study by Hasselkus and Merrick [34]. Cheng, Mak, Lau, Ng and Lam [24] examined positive gains and found out that caregivers with positive mind set felt closer bonding with person with NCD. Opportunity to help other caregivers and people who care were also found to be gains [24].

In a qualitative study by Netto, Jenny and Philip of the gains experienced by caregivers improvement in relationship and ability to interact better were found to be the second common gain in caregiving [25]. The impact of aspects of couple relationships was explored by Merrick, Camic and O’Shaughnesssy [44] in a qualitative study. Five facilitative themes were
discovered by the experiences about the impact of NCD and of the process of adjusting when living with an individual with NCD; 1) Foundations, commitment to each other, shared history and togetherness; 2) Altered Structures, bonding over the problems; 3) Self-reconstruction, struggling with illness and what is lost and what is still remain; 4) Flexible Scaffolding, maintaining partner’s identity; 5) Reviewing the plans, being aware of self and other [44]. Fluctuating between the positions of letting go of what has been lost and holding on to what is remaining in a couple’s relationship were acknowledged also by caregivers [44].

In a study by Grover, Nehra, Malhotra and Kate, getting social support were found to increase motivation on caregiving [27]. Papastavrou et al. found that problem-solving and logical analysis were found to help perhaps more in caregiving a person with NCD than treatment aimed to emotional side [32]. Giebel and Sutcliffe [45] have studied IADL (Instrumental Activities of Daily Living) performance of persons with mild NCD in their cross-sectional study. Engaging in hobbies and active social life were positively associated with carer and person with NCD well-being [45]. In a study of predictors of resilience by Gaugler et. al [43] those caregivers who utilized formal and informal support and resources were more resilient than caregivers who did not search help or support. The use of support was found to be a facilitative aspect in caregiving [43]. Resilience was also found to be a predictor of transitions like nursing home placement in caregiving and facilitating the possibility staying at home [43]. Married caregivers and caregivers with social support were found to have higher scores in positive role of caregiving than unmarried in study by Grover et.al. [27]. External support was found as on important feature of resilience to caregivers in study by Joling et. al. [33]. Social support was also found to be associated with low depression of caregivers in study of effects of spirituality and self-efficacy by Lopez et. al. [26].

Soilemezi, Drahota, Crossland, Stores and Costall [46] have examined the meaning of home when caregiving a person with NCD based on the idea of ‘Ageing In Place’ in their qualitative research. Research was done by observing and interviewing caregivers at home. Home was found to be a very important place for caregivers and considered to be one essential features of caregiver’s well-being [46]. The meaning of home was also changing when the other in the dyad had NCD because of assistive equipment for example [46]. Safe home environment for caring was considered to be a facilitative aspect of caregiving [46]. Caregivers also found a place of their own at home as an important place for relaxation [46].
In a study by Donnellan, Bennett and Soulsby the findings reveal that a resilient carer was more likely also be supported by family and especially by friends [35]. Deist and Greeff [47] have explored factors associated with resilience by mixed-methods in families taking care a person with NCD. Social support, positive communication, acceptance, optimism, hardiness and connectedness in the family as well effective management of symptoms were found to facilitate the resilience process. Family adaptation was found to have positive correlation with communication in the family [47].

**Facilitating aspects of occupation (activity, task and occupation) when taking care a person with NCD**

In a study of positive and negative effects of caregivers by Robertson et al. lower levels of problems in behaviours and little help with activities of daily living of person with NCD were associated with better quality of relationship experienced by caregivers [37]. The absence of problems in the behaviours of the person with NCD were found to have a positive effect on caregivers well-being in the cross-sectional study of Lopez, Romero-Moreno, Marquez-González and Losada [26]. Less problems in the behaviours of person with NCD were also found to impact on the quality of relationship and for the quality of life in the research by Farina et. al. [30] Joling et. al [33] and Quinn et. al. [40].

In systematic review by Farina et. al. carers possibility to participate in activities and to have own time out of caring time was found to have a positive effect on carers QoL [30]. In a study by Joling et al., being able to have good time together was found to be essential feature of resilience for caregivers [33]. Merrick, Camic and O´Shaughnessy [44] have examined how couples construct their relationship when dyad is having NCD. New flexible ways of caregiving such as bonding over the problems and attempting to maintain partners identity were found to facilitate caregiving [44].

Care receivers’ temporary and comprised moments of feeling good during daily occupations were source of well-being for both in dyad in the qualitative study of daily occupations of caregiving a person with NCD by Hasselkus and Murray [34]. Ordinary daily occupations were contributing to well-being for both caregiver and care receiver. Daily occupations served also a way to evaluate and monitor care receivers well-being and the care caregiver was providing
Giebel and Sutcliffe [45] studied daily activities contributing well-being in people with NCD and their carers. Early management have found to have a positive effect on caregiving. Engaging in individual hobbies and activities were found to improve both of the dyad well-being [45]. In a study of resilience by Joling et. al enjoying spending time together was found to be a source of resilience [33]. While resilience and transitions were researched by Gaugler, Kane and Newcomer in their quantitative study these authors also found that caregivers who spent more time providing care were likely to be more resilient [43].

**Facilitating aspects of occupational performance (transaction of the person, environment and occupation) when taking care a person with NCD**

Occupational performance is the outcome of the transaction of the person, environment and occupation. As a facilitator the closer overlap of these elements, the more harmoniously they are assumed to be interacting [1]. Personal factors facilitating occupational performance found were many. Gains in caregiving like accepting the disease, having found meaning and sense of purpose in caregiving [24,25,27,29] were found to be essential factors that supports the caregivers role. Feelings of gratitude and possibility for personal growth were increasing the fit of occupational performance of caregiving [25, 36, 40]. These personal aspects were keys to find caregiving as a positive occupation and had a positive effect on relationship between dyad [24,30,36,39]. Caregivers with personal aspects like religiosity, spirituality and self-efficacy were found to be less vulnerable to negative impact on caregiving [26,28,29]. In the research of the concept of resilience was found that less problems in behaviour of person with NCD and feeling competent as a caregiver were increasing the positive experience of caregiving [25,33, 35,46,48]. Caregivers ability to use positive strategies, coping and using a facilitative style in caregiving were seen to have positive effect on caregivers occupational performance [24,31,32,36,45].

The good quality of relationship of caregiver and person with NCD was found to have an impact on both of the dyads quality of life and was facilitating occupational performance of both caregiver and person with NCD. Good quality of relationship was having positive effect on the care that caregiver provided and for the experience how caregiving was found [25,33,36,39,40,41,42,43,45,47]. Aspects dealing with occupational performance of a person
with NCD not having problems in his/her behaviour were found facilitate caregivers occupational performance [26,32,33,40,42,45]. Daily occupations were found to be a source of well-being and were increasing the harmony of caregivers and care receivers occupational performance [33,34,45]. Caregivers and care receivers own hobbies were also found to facilitate occupational performance of both [44].

**Discussion**

The aim of this research was to identify facilitative aspects of the person, environment and occupation that have an impact on caregivers of person with NCD occupational performance. A scoping review was chosen to include a variety of research methods and types in order to be able to map the key findings [23]. The PEO-model by Law et al. [1] was used to categorise the results. From 24 studies that were included, facilitative aspects of person were found from 16 studies, facilitative aspects of environment (including relationship and culture) from 17 studies and studies having occupational facilitators were found from 9 studies. These findings suggest that these facilitators may have some commonalities when caregiving a person with NCD.

The main finding was the importance of the relationship. The quality of relationship was found to have an impact on the quality of life and well-being of both, to the care and caregiving style that caregiver provides [24,25,30,33,34,36,38,39,40,41,42,44]. Relationship could be seen as an overlap of caregivers and care receivers PEO-systems. Relationship is influenced by many aspects including recent and past quality of relationships, personal aspects, demographics, social network and culture among others. NCD is having an effect on communication, memory and behaviour that weakness the mutuality [26,30,31,33,34,40] which was found to be a facilitative aspect of relationships quality. Interventions to support relationship between person with NCD and caregivers were requested [25,32,33,36,39,40,41,42,43,45,48].

The cognitive deficiency of people with NCD affects capacity to cope with daily living and increases the need for support. Caregivers’ personal aspects such as self-efficacy, spirituality, optimism and resilience increase the likelihood that she/he can compensate for shortages of
occupational performance of the person with NCD. Caregivers adaptation to the 
circumstances, acceptance of the disease, were found to be key in balancing occupational 
performance of caregiving a person with NCD. Interventions that consider caregivers personal 
aspects are recommended [24,25,26,28,30, 32,33,35].

The most influential impact on occupational performance found were problems in behaviour 
of the person with NCD [26,32,40]. These behavioural problems like wondering, apathy and 
aggression stretch caregivers’ ability to learn new skills like flexibility and positive coping 
strategies that were found to facilitate caregivers occupational performance. Different styles 
of caregiving were also identified to have an effect on caregiving. Personalized interventions 
that are tailored to dyads’ needs were recommended [26,32,33,40,42,45].

Caregivers who were active in finding social support and were supported by the family and 
friends were managing better in caregiving [24,32,33,44,47]. The role of daily occupations 
were found to be a source of well-being for both in a dyad. Having own hobbies and social 
groups were also found to facilitate occupational performance of the dyad [40,43,44].

Results of this scoping review were compared mainly with the results of the Lancet 
Commissions Dementia Prevention, Intervention and Care review by Livingston et. al (2017) 
meta-analysis[48] which represents the best evidence available have been used to make 
those recommendations. General results of the Lancet Commissions review were 
recommendations for interventions, for prevention of the disease, individualised care when 
having NCD, interventions to reduce risk for depression for caregivers, management of 
neuropsychiatric symptoms of NCD, treatment to cognitive symptoms of person with NCD, 
future planning and technology and care management were also highlighted [48]. Results of 
the scoping review, compared to this meta-analysis, are comparable to support interventions 
which support facilitative aspects of occupational performance of caregiver of person with 
NCD. From the Lancets meta-analysis family caregivers were at high risk for depression and 
they were reported lower quality of life than average. By enabling to live longer time at home 
with the person with NCD management with the disease was seen as an essential feature of 
intervention[48]. In this scoping review interventions were not included but caregivers who 
attended support and educational programs were finding gains in caregiving and had less 
depression [26, 45].
Interventions to decrease caregivers stress such as the Seattle Protocol have found evidence for training both the person with NCD and caregiver to understand interpersonal and environmental aspects and by doing exercise with pleasant activities for both individuals of the dyad [50]. The importance of the relationship and high level of mutuality between caregiver and care receiver have found to be the most important facilitative aspect in this review which have a positive effect into the relationship and well-being of both of the dyad and also support caregivers role as a result of this scoping review [25,32,33,36,39,40,41,42,43,45,48]. The role of daily occupations and having good time together were also found as facilitative aspects [33,34,45] as well as hobbies and active social life [33,45].

Evidence for later admissions to care homes have been shown through tailored psychological multi component approaches such as the Resources to Enhance Caregivers Health (REACH)[53, 54]. REACH II focuses on five areas that are linked to caregiver health outcomes: safety, self-care, social support, education, and skills training with problem behaviours of person with NCD [55]. Safety issues were not highlighted in the current review because lack of the research found from environmental facilitators. Care receivers’ need for help in self-care was found to be one critical aspect associated with lower quality of relationship experienced by caregivers. [40].

Fewer problems in the behaviours of a person with NCD were found to be one of the most important aspects that facilitate caregiving [30,40,42,43]. Social support was found to be a particularly facilitative aspect where problematic behaviours are evident. Caregivers who utilized formal and informal support and resources were more resilient than caregivers who did not search help or support [24,30,33]. Caregivers with positive mind set were more active in caregiving and as well in finding support [31]. Social-support as family adaptation was found to be to be one of key aspect of resilience[47]. Concepts like resilience were found [33,43] to be able to target to key health transitions such as delaying nursing home placement in a results of this review [35, 43]. Consistent with this, specialised individual psychological based interventions to cope better with behavioural problems of NCD with at least 6 sessions have found some evidence by Lancet commissions review [55, 59].

As a part of the REACH project, positive aspects of caregiving were researched by Tarlow et. al [56] to develop a measure of positive aspects of caregiving. Due to that research caregivers
felt generally positive about their caregiving experience. Most caregivers also reported that caregiving enabled them to appreciate life more, develop a more positive attitude toward life as well strengthened their relationships with others[56]. Acceptance-based and emotion-focused approaches have also found evidence in the Lancet’s review for caregivers to help them identifying their role as a caregiver [48].

Results of the REACH study and acceptance-based and emotion-focused approaches are in the line with the results of this scoping review. Positive aspects of caregiving [24, 25, 27] togetherness during daily occupation[45], optimistic attitude, high self-efficacy [26,31] and contingency [31]were found to be facilitative aspects on coping better with problem behaviours [31,33]. Those caregivers who experienced more gains [24] in caregiving were also found to cope better with burden in caregiving[27].Religiosity and spirituality were also found as a source by emerging stronger in caregiving experience [26, 28]. Acceptance of the disease was found to be the most important aspect to experience positive gains in caregiving and may helped caregivers to reframe stressful situations by this review [29].

Limitations

One limitation to this scoping review was in the search method. Test searches were done to Occupational Therapy’s databases but no relevant articles were found. Studies found were dealing mainly with interventions that were not included. Test searches with different search words were also done to found articles that answer to research questions. Search words: “activities” and “tasks” “occupational performance” or “performance” were used in test searches but hits that were not relevant were found. Articles found were dealing with activities, tasks or occupational performance of persons with NCD; not caregivers or caregiver’s burden or interventions. Especially the lack of research about occupation as a facilitative aspect was a limitation that may influenced results of the study. Searches from different databases or grey literature could have Identified further literature.

The aim of the inclusion and exclusion criteria is to optimize the external and internal validity of the study. Well-selected criteria will increase the likelihood of finding associations between intervention and outcomes [60]. The exclusion and inclusion criteria that were established tried to find commonalities of the facilitative aspects of caregiving that could be generalized. Research dealing only with specific ethnic background, gender or relational issues only or
specific healthcare system of chosen country were left out. This exclusion criteria had limitations because gender, ethnical background and the type of relation have been found to have an influence on occupational performance [40,48].

In the method's section more detailed documentation of the searches would have increased the clarity and transparency of the study and therefore increased studies trustworthiness. Doing data extraction alone increases the risk of bias which could have been diminished by having other opinion from more experienced researcher.

Extraction of the information was done by a charting table in which chosen studies were summarised. In this scoping review variety of different types of studies were included. All studies included were not high in quality. In qualitative studies sample sizes in some studies were quite small [25, 33, 36, 41, 44, 46] and some were as well homogenous due the ethnical background and gender [25, 26, 27, 29, 37,41]. Formulation of the question used were quite general [32] which can lead to wrong interpretation.

There were also limitations designs of some studies [28, 32]. Assessment scales were not linked to behaviours of well-being [28, 32]. Assessments used did not provide enough detail in some of the studies [35, 42]. The hierarchy of evidence of the studies were not highlighted when extracting the results [62] but there were studies also with high(er) quality such as three systematic reviews [30, 39, 40].

Being a novice researcher stresses that mistakes could have been done in the research process. Also using English language which is not a mother tongue makes mistakes possible in the extraction and coding of PEO content.

**Ethical considerations**

Ethical standards like Declaration of Helsinki provide guidance in medical research involving human subjects [63]. This study was a literature review and did not involve straight contact with people. All the chosen studies were from scientific journals that have a high quality of standards that increases the reliability of the studies included. Because of many limitations in methodology and transparency of the process the results of
this scoping review may have limitations in trustworthiness. The aim of the study was to find facilitative aspects that could be common when taking care of a person with NCD. The aspect of commonality was not compared to the research with ethnical or cultural differences. Study does not offer answer to that research question which weakens the quality of research done.

Doing research with people that have cognitive deficiency like NCD has many difficulties. Participating into research requires understanding of the information about research and that is unlikely in mid-and severe stages of dementia [64]. This scoping review was concentrating mainly on caregivers but six articles where both of the couples were participating were included. Because data provided by caregivers commonly differs from data provided by people with dementia researchers are increasingly encouraged to involve them as study participants in research on care and services [64]. Having a cognitive deficit like people with NCD could still have an opinion and right to be able to take part of the research that is improving their care and services if they are willing to. People with NCD are a particularly vulnerable group. Ethical consideration should be preceded carefully of predictable risks and burden that may be caused to the individuals with NCD [63,66].

Majority of the studies were done by interviewing the caregivers. Interviewing is a flexible way to gather information about experiences, beliefs and behaviours but its has disadvantages. Interviewing may cause stress especially when having emotional issues that need to be carefully considered by interviewer [60]. The relationship between participant/s and the researcher may have also influenced into the interview. There is a risk of interviewee bias during interviewing and that can compromise the validity of the findings. Also people who are pleased with the aim that is searched are more willing to take part into research that may have effect to the outcome [60]. When interviewing a person with NCD special caution should be applied to avoid possible misunderstandings [65].

**Implications for occupational therapy**

The aim of this study was to find facilitative aspects that could be used when planning interventions or ways to support caregivers when the person who is being cared for has NCD. The finding regarding the importance of relationship supports the need to evaluate the state of relationship and other factors that have an influence on caregiving. Understanding of the
nature and form of relationships could help targeting the interventions to fit more precisely to dyads needs. By evaluating the role of daily occupations dyads collaboration could be supported better.

Identification of caregivers’ personal aspects like values, attitudes and skills could help occupational therapist to support the caregiver, facilitating caregiving style and improving the skills that are needed in caregiving. Evaluation could support to even more personalized interventions to help caregiving a person with NCD. Facilitative aspects of environment when having a NCD could be interesting research area because environmental interventions like technology are seen as an important way to support people with NCD and their families in the future [55, 59].

These findings encourage the use of occupational therapy to support both caregiver of person with NCD and care receiver. Despite the concentration of interventions in compensating for challenging aspects of caregiving, more holistic approach to support caregivers is suggested. Support and interventions where the role of relationships, possibilities to enable caregivers’ personal growth and finding joy within daily occupations of caregiving could be utilized.

References


17. Donovan ML, Corcoran MA. Description of Dementia Caregiver Uplifts and Implications for Occupational Therapy. American Journal of Occupational Therapy. 2010;64(4):590-


1. Figure PRISMA figure
2. Table 1. Summary of Articles1 and extracted themes.
3. Appendix - Journal Author Guidelines
Records identified through 4 database searching
CINAH1 176
AGELINE 146
Psych INFO 473
PubMed 727
(n = 1522)

Exclusion: interventions, assessments, people with NCD not living at home with caregiver, not dementia, not facilitating aspects (burden, stress etc.)

Inclusion: facilitating aspects (facilitate, enable, motivate, gain, uplift support, improve) in caregiving with persons with dementia

Records after inclusion and exclusion criteria after reading headings and abstracts (n = 75)

Duplicates (n = 26)

Full-text articles assessed for eligibility (n = 49)

Full-text reviewed for inclusion/exclusion (n = 31)

Studies included in the scoping review (n = 24)

Full-text articles excluded, caregiving in certain country or certain ethnic group focusing single situations in caregiving like getting dg. (n = 18)

Full-text articles excluded not relevant (n = 7)

Table 1. Summary of Articles and extracted themes.

<table>
<thead>
<tr>
<th>Reference number</th>
<th>Authors (year), title, journal</th>
<th>Subject and country</th>
<th>Purpose</th>
<th>Participant</th>
<th>Method (data collection and data analysis)</th>
<th>Limitations</th>
<th>Results/conclusion (PEO factor)</th>
</tr>
</thead>
<tbody>
<tr>
<td>24</td>
<td>Cheng, Mak. Lau and Ng and Lam (2016)</td>
<td>Alzheimer's disease dementia caregivers feelings Hong Kong China</td>
<td>To discover positive gains when caregiving a person with dementia</td>
<td>57 caregivers</td>
<td>Qualitative thematic analysis of caregivers diary records of daily living</td>
<td>Most of the people participating were daughters and mothers other combinations were few</td>
<td>Ten themes were described as gains 1. Insights about dementia and acceptance of disease (P) 2. A sense of purpose and role commitment (P) 3. Feelings of gratification and gratitude (P) 4. A sense of mastery (P) 5. Increased patience and tolerance (P) 6. Cultivating a positive mind set (P) 7. Learning to Let Go (O) 8. A closer bonding (E) (OP) 9. Finding support (E) 10. Possibility to help other caregivers (E) Means to identify positive gains should be promoted</td>
</tr>
<tr>
<td>25</td>
<td>Netto, Jenny and Philip (2009)</td>
<td>Investigate how caregivers of persons with dementia experience gains Singapore</td>
<td>Burden, caregiving, dementia, gain, positive, strain</td>
<td>12 caregivers</td>
<td>A qualitative design, grounded theory approach, semi-structured, face-to-face interviews</td>
<td>Small and homogeneity sample size Researcher as an instrument in data collection</td>
<td>Most common gain was 'Personal Growth: more patient or understanding, becoming stronger or more resilient, having increased self-awareness and being more knowledgeable. (P) Second gain &quot;Gains In Relationships' improvement in relationship and ability to interact better (E) (OP) The third gain 'Higher-level gains like spirituality and enlightened way of living (P) Findings supports to more holistic approach to support caregivers of persons with dementia where personal growth, improvement in relationship as well more enlightened way of living with dementia is possible.</td>
</tr>
<tr>
<td>26</td>
<td>Lopez, Romero-Moreno, Marquez-González and Losada (2012)</td>
<td>Analyse how combined effect of spirituality and self-efficacy is associated with caregivers well-being Spain</td>
<td>Dementia Caregivers Spiritual Meaning Competence Stress Process Coping Anxiety Depression</td>
<td>122 caregivers</td>
<td>Cross sectional study</td>
<td>Convenience-based sample of participants limits the generalization of these findings Limitation of the assessments Limitation of the design (cross-sectional) causal inferences are not possible</td>
<td>Spirituality and self-efficacy (P) had a positive effect on caregivers' well-being A high sense of spirituality and self-efficacy combination was associated with lower levels of depression in caregivers. (P) Behaviour problems of person with dementia (O) were associated with high levels of anxiety Implications to interventions to cope better with problem behaviours by strengthening the social support network, finding spiritual meaning within the caregiving experience may help to lower depression level of caregivers of person with dementia.</td>
</tr>
<tr>
<td>27</td>
<td>Grover, Nehra, Malhotra, and Kate (2017)</td>
<td>Aim was to evaluate experience of positive aspects of caregiving and how it is</td>
<td>Caregivers Psychology Dementia</td>
<td>55 caregivers</td>
<td>Quantitative using Structured questionnaires/scales Assessments like Scale for Positive Aspects of Caregiving</td>
<td>Small sample size Heterogeneous aetiologies by sample caregivers from specific clinic</td>
<td>The mean Scale for Positive Aspects of Caregiving Experience (SPACE) domain score was highest for motivation for caregiving role (P) followed by satisfaction in caregiving (O), personal gains (P), self-esteem (P) and social aspect of caring (E).</td>
</tr>
<tr>
<td>Study</td>
<td>Design</td>
<td>Sample Size</td>
<td>Methodology</td>
<td>Results</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>----------------------------------------------------------------------</td>
<td>------------------------------------------------------------------------</td>
<td>-------------</td>
<td>----------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Positive Aspects of Caregiving Experience among Caregivers of Patients with Dementia</td>
<td>Mixed methods using interviews and questionnaires</td>
<td>111 dyads</td>
<td>Thematic qualitative analysis conducted based on interviews</td>
<td>Findings suggest that religiosity (P) of both the caregiver and the person with dementia have an affect on the PWDs Quality of life (OP). Findings stresses the importance of the caregiver to understand the values of person with dementia (P) concerning religion as it may serve as a coping mechanism for dealing with illness like dementia</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nagpal, Heidb, Zarita and Whitlatchc (2014)</td>
<td>Mixed methods using interviews and questionnaires</td>
<td>11 dyads</td>
<td>Homogeneous sample group strategies and values that were researched could be beneficial to all caregivers</td>
<td>These findings were the same despite of caregiver gender, age, race, level of education, or length of caregiving. Those caregivers who had found meaning to care (P) had altruistic values and they lived by these values. (P) They had faith in a higher power (P), they loved their spouses (E), (OP) and derived strength from past challenges (P)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shim, Barroso, Gillis, and Davis (2013)</td>
<td>Thematic qualitative analysis conducted based on interviews</td>
<td>11 caregivers</td>
<td>One time interview</td>
<td>Findings suggest to share positive stories of caregiving to help other caregivers and care recipients. Caregiver's attitudes of caregiving can have a significant influence to attitude toward the care recipient. Positive stories could also help caregivers to reframe caregiving as a meaningful experience</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Farina, Page, Daley, Brown, Bowling,Basset, Thurstone,Livingston, Knapp, Murray and Banerjee (2017)</td>
<td>Systematic review Quantitative, qualitative, and mixed-methods studies</td>
<td>41 studies (n=5539)</td>
<td>Lack of the data how ethnic and cultural factors effects Studies where the QOL was not a primary outcome Heterogeneity and missing information between groups. The tool was used in summarized the results Standardized effect sizes were not calculated</td>
<td>10 themes were identified to have an effect on QOL of family caregivers of people with dementia. 1. demographics; (E) 2. carer–patient relationship (E) (OP) 3. dementia characteristics (P) 4. demands of caring (O) 5. carer health (P) 6. carer emotional well-being (P) 7. support received; (E) 8. carer independence; (P) 9. carer self-efficacy (P) 10. future (E)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Because the quality and level of evidence supporting each theme varied there is need for further research which factors predicts QOL of caregiver and how it could be measured.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Title</td>
<td>Design</td>
<td>Sample</td>
<td>Measures</td>
<td>Data Collection</td>
<td>Analysis</td>
<td>Findings</td>
</tr>
<tr>
<td>-------</td>
<td>-------</td>
<td>--------</td>
<td>--------</td>
<td>----------</td>
<td>----------------</td>
<td>---------</td>
<td>----------</td>
</tr>
<tr>
<td>31 Contador, Fernández-Calvo, Palenzuela, Miguéis and Ramos, (2012)</td>
<td>Prediction of burden in family caregivers of patients with dementia: A perspective of optimism based on generalized expectancies of control</td>
<td>Qualitative</td>
<td>Caregiver burden Family dementia optimism</td>
<td>To investigate the predictors of burden for informal caregivers of persons with dementia</td>
<td>130 caregivers</td>
<td>Quantitative Statistical analysis were performed</td>
<td>Hours of taking care on daily basis were not controlled and generalization of the results to population in general was not possible</td>
</tr>
<tr>
<td>32 Papastavrou, Tsangari, Karayiannis, Papacostas, Elstathiou and Sourtzi, (2011)</td>
<td>Caring and coping: The dementia caregivers</td>
<td>Mixed-methods</td>
<td>Research caregivers' coping styles and their impact on burden and depression</td>
<td>Alzheimer Coping Caring Burden Caregiver</td>
<td>172 caregivers</td>
<td>Quantitative A cross-sectional correlation study Four measuring instruments were used</td>
<td>Design of the study Formulation of the questions asked to have focus on caregiving in general</td>
</tr>
<tr>
<td>33 Joling, Windle, Dröes, Huisman, Hertogh, Cees and Woods (2017)</td>
<td>What are the essential features of resilience for informal caregivers of people living with dementia? A Delphi consensus examination</td>
<td>Mixed-methods</td>
<td>To identify essential features of resilience Address new insights and limitations how it should be promoted</td>
<td>Resilience Dementia Family Caregivers Delphi method</td>
<td>13 caregivers 17 professionals</td>
<td>A Delphi consensus study was conducted by panel of caregivers and healthcare experts</td>
<td>Expert panel members were all high educated which is not always relevant situation with stakeholders</td>
</tr>
<tr>
<td>34 Hasselkus and Murray (2007)</td>
<td>Everyday occupation, well-being, and identity: the experience of caregivers in families with dementia</td>
<td>Quantitative</td>
<td>Dementia Employment Personal Satisfaction Caregivers -- Psychology USA</td>
<td>The purpose of this study was to gain understanding of the nature of the daily occupations of caregivers for family members with dementia</td>
<td>33 caregivers</td>
<td>Qualitative telephone interviews, analysed by using phenomenological approach</td>
<td>Sample consisted of self-selecting and educated caregivers family caregiver's subjective</td>
</tr>
</tbody>
</table>
### The American Journal of Occupational Therapy

**31**

related to the caregivers’ perception of severity of dementia stage

connection and mutuality with care receiver. (E)

A sense of reciprocity was found especially satisfying. (E)

Everyday occupation holds promise for contributing to the relative well-being of both caregivers and care receivers and for facilitating continuity of relationships and identity for the caregiver.

**35**

Donnellan, Bennett, and Soulsby (2015)

What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study

A sense of reciprocity was found especially satisfying. (E)

Everyday occupation holds promise for contributing to the relative well-being of both caregivers and care receivers and for facilitating continuity of relationships and identity for the caregiver.

**36**


The positive aspects of the caregiving journey with dementia: Using a strengths-based perspective to reveal opportunities

A resilient carer was defined to be positive (P) active in maintaining relationship (E) and loved one’s former self. (P)

They were knowledgeable (P) and well supported by family and especially by friends (E)

More ecological models of resilience were proposed.

**37**

Robertson, Zarit, Duncan, Rovine and Femia (2007)

Family caregivers’ patterns of positive and negative affect

Five themes emerged 1. possibility to give back (P) 2. personal growth (P) 3. discovery of inner strengths (P) 4. a sense of competence (P) 5. a change for a closer relationship (E). (OP) and loyalty to the care receiver. (P)

There were differences between husbands and wives or adult children in experiences.

By recognizing positive aspects of caring may help health care practitioners to improve their relationship with family caregivers to see them as partners.

That would also benefit family caregivers. Strengths-based perspective could also be used in management and assessments approaches.

| Donnellan, Bennett, and Soulsby (2015) | UK | Assess whether spousal dementia caregivers can accomplish resilience and stress which assets and resources facilitate or hinder | 20 spousal caregivers | Qualitative interviews with grounded theory approach | Participants were recruited mainly from dementia support group  Assessments, resources and classification system used may be too simplistic to show the point of facilitating aspects after they may hinder |
| Peacock, Forbes, Markle-Reid, Hawranik, Morgan, Jansen, Leipert and Henderson (2010) | Canada | The aim of this study was to have debate of the positive aspects of caring a family member with dementia related to qualitative findings of six focus groups | 6 focus groups (n=36) and 3 interview | Qualitative study based on interviews | Participants were using formal care or community services |
| Robertson, Zarit, Duncan, Rovine and Femia (2007) | USA | Study examined positive and stressful aspects of family caregiving as predictors of caregivers’ patterns of positive and negative affect. | n=234 | Quantitative Cross-sectional study | The homogeneous sample  Alternative explanations for phenomena are possible  Group allocation was made using median split |

The American journal of occupational therapy

**31**

related to the caregivers’ perception of severity of dementia stage

connection and mutuality with care receiver. (E)

A sense of reciprocity was found especially satisfying. (E)

Everyday occupation holds promise for contributing to the relative well-being of both caregivers and care receivers and for facilitating continuity of relationships and identity for the caregiver.

**35**

Donnellan, Bennett, and Soulsby (2015)

What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study

A sense of reciprocity was found especially satisfying. (E)

Everyday occupation holds promise for contributing to the relative well-being of both caregivers and care receivers and for facilitating continuity of relationships and identity for the caregiver.

**36**


The positive aspects of the caregiving journey with dementia: Using a strengths-based perspective to reveal opportunities

A resilient carer was defined to be positive (P) active in maintaining relationship (E) and loved one’s former self. (P)

They were knowledgeable (P) and well supported by family and especially by friends (E)

More ecological models of resilience were proposed.

**37**

Robertson, Zarit, Duncan, Rovine and Femia (2007)

Family caregivers’ patterns of positive and negative affect

Five themes emerged 1. possibility to give back (P) 2. personal growth (P) 3. discovery of inner strengths (P) 4. a sense of competence (P) 5. a change for a closer relationship (E). (OP) and loyalty to the care receiver. (P)

There were differences between husbands and wives or adult children in experiences.

By recognizing positive aspects of caring may help health care practitioners to improve their relationship with family caregivers to see them as partners.

That would also benefit family caregivers. Strengths-based perspective could also be used in management and assessments approaches.

| Donnellan, Bennett, and Soulsby (2015) | UK | Assess whether spousal dementia caregivers can accomplish resilience and stress which assets and resources facilitate or hinder | 20 spousal caregivers | Qualitative interviews with grounded theory approach | Participants were recruited mainly from dementia support group  Assessments, resources and classification system used may be too simplistic to show the point of facilitating aspects after they may hinder |
| Peacock, Forbes, Markle-Reid, Hawranik, Morgan, Jansen, Leipert and Henderson (2010) | Canada | The aim of this study was to have debate of the positive aspects of caring a family member with dementia related to qualitative findings of six focus groups | 6 focus groups (n=36) and 3 interview | Qualitative study based on interviews | Participants were using formal care or community services |
| Robertson, Zarit, Duncan, Rovine and Femia (2007) | USA | Study examined positive and stressful aspects of family caregiving as predictors of caregivers’ patterns of positive and negative affect. | n=234 | Quantitative Cross-sectional study | The homogeneous sample  Alternative explanations for phenomena are possible  Group allocation was made using median split |

The American journal of occupational therapy

**31**

related to the caregivers’ perception of severity of dementia stage

connection and mutuality with care receiver. (E)

A sense of reciprocity was found especially satisfying. (E)

Everyday occupation holds promise for contributing to the relative well-being of both caregivers and care receivers and for facilitating continuity of relationships and identity for the caregiver.

**35**

Donnellan, Bennett, and Soulsby (2015)

What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study

A sense of reciprocity was found especially satisfying. (E)

Everyday occupation holds promise for contributing to the relative well-being of both caregivers and care receivers and for facilitating continuity of relationships and identity for the caregiver.

**36**


The positive aspects of the caregiving journey with dementia: Using a strengths-based perspective to reveal opportunities

A resilient carer was defined to be positive (P) active in maintaining relationship (E) and loved one’s former self. (P)

They were knowledgeable (P) and well supported by family and especially by friends (E)

More ecological models of resilience were proposed.

**37**

Robertson, Zarit, Duncan, Rovine and Femia (2007)

Family caregivers’ patterns of positive and negative affect

Five themes emerged 1. possibility to give back (P) 2. personal growth (P) 3. discovery of inner strengths (P) 4. a sense of competence (P) 5. a change for a closer relationship (E). (OP) and loyalty to the care receiver. (P)

There were differences between husbands and wives or adult children in experiences.

By recognizing positive aspects of caring may help health care practitioners to improve their relationship with family caregivers to see them as partners.

That would also benefit family caregivers. Strengths-based perspective could also be used in management and assessments approaches.

<p>| Donnellan, Bennett, and Soulsby (2015) | UK | Assess whether spousal dementia caregivers can accomplish resilience and stress which assets and resources facilitate or hinder | 20 spousal caregivers | Qualitative interviews with grounded theory approach | Participants were recruited mainly from dementia support group  Assessments, resources and classification system used may be too simplistic to show the point of facilitating aspects after they may hinder |
| Peacock, Forbes, Markle-Reid, Hawranik, Morgan, Jansen, Leipert and Henderson (2010) | Canada | The aim of this study was to have debate of the positive aspects of caring a family member with dementia related to qualitative findings of six focus groups | 6 focus groups (n=36) and 3 interview | Qualitative study based on interviews | Participants were using formal care or community services |
| Robertson, Zarit, Duncan, Rovine and Femia (2007) | USA | Study examined positive and stressful aspects of family caregiving as predictors of caregivers’ patterns of positive and negative affect. | n=234 | Quantitative Cross-sectional study | The homogeneous sample  Alternative explanations for phenomena are possible  Group allocation was made using median split |</p>
<table>
<thead>
<tr>
<th>#</th>
<th>Author(s)</th>
<th>Title</th>
<th>Year</th>
<th>Country</th>
<th>Design/Methods</th>
<th>Participants</th>
<th>Results/Findings</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>38</td>
<td>Corcoran (2011)</td>
<td>Dementia Caregiving Typology: A Cognitive and Behavioral Typology Associated With Dementia Family Caregiving Gerontologist</td>
<td>2011</td>
<td>USA</td>
<td>Systematic review of the influence of relationship factors</td>
<td>31 caregivers</td>
<td>The qualitative analytic approach based on grounded theory Results can not be transferred to different ethnic groups and study involves only short time of being a caregiver Four caregiving styles: facilitated style (P), balancing style (P), advocating (P), directing (P) Findings support personalized caregiver interventions that are tailored to unique circumstances of each caregiver dyad.</td>
<td>Evidence that qualities of relationship between person with dementia and caregiver have an impact to the experience living with dementia was found. Due the results integrative theoretical framework was proposed. Different forms of relationship were covered. Continuity, Reciprocity, Detachment, Duty. Findings request intervention to support quality of relationship between person with dementia and caregiver. (E)</td>
</tr>
<tr>
<td>39</td>
<td>Ablitt, Jonesc, and Muersc (2009)</td>
<td>Living with dementia: A systematic review of the influence of relationship factors</td>
<td>2009</td>
<td>UK</td>
<td>Qualitative interview of dyads having dementia</td>
<td>161 dyads</td>
<td>The majority of the studies examined quality current relationship only impact of the mood to results when interviewing persons just one study included the perspectives of both caregiver and care-recipient. Findings points out that caregiving can have an impact on relationship between caregiver and care-recipient. Quality of current relationship and before caregiving is having an impact on caregivers well-being and to the care that caregivers provide. By caregivers point of view help with activities of daily living and level of behavioral problems with care recipient were found to influence most to their quality of relationship. Gender and relationship (spouse, child ext) may influence also to quality of relationship. Study recommends to gain more understanding of the role of relationship in caregiving to develop better interventions that have an effect on well-being of both caregivers and care-recipients. LIke.</td>
<td></td>
</tr>
<tr>
<td>40</td>
<td>Quinn, Clare and Woods (2009)</td>
<td>The impact of the quality of relationship on the experiences and wellbeing of caregivers of people with dementia: a systematic review.</td>
<td>2009</td>
<td>UK</td>
<td>Systematic review of the influence of relationship factors in dementia caregiving</td>
<td>1062 participants</td>
<td>Findings show that caregiving can have an impact on relationship between caregiver and care-recipients. Quality of current relationship and before caregiving is having an impact on caregivers well-being and to the care that caregivers provide. By caregivers point of view help with activities of daily living and level of behavioral problems with care recipient were found to influence most to their quality of relationship. Gender and relationship (spouse, child ext) may influence also to quality of relationship. Study recommends to gain more understanding of the role of relationship in caregiving to develop better interventions that have an effect on well-being of both caregivers and care-recipients. LIke.</td>
<td></td>
</tr>
<tr>
<td>41</td>
<td>Daley, O’Connor, Shirk and Beard (2017)</td>
<td>In this together’ or ‘Going it alone’: Spousal dyad approaches to Alzheimer’s disease</td>
<td>2017</td>
<td>USA</td>
<td>Mixed method approach of dyads taking approaches of We/us I/Me</td>
<td>11 spousal couples</td>
<td>Small sample size Homogenous group due the ethnical background and gender. Dyads with We/Us approach expressed more positive aspects of caregiving than I/Me dyad. Findings suggest that the approach is not significant differences between groups on other variables than relationship and spousal caregiver. Positive Aspects of Caregiving We/Us approach may be protective characteristic of spousal dyads when having Alzheimer’s disease.</td>
<td>Findings show that caregiving can have an impact on relationship between caregiver and care-recipients. Quality of current relationship and before caregiving is having an impact on caregivers well-being and to the care that caregivers provide. By caregivers point of view help with activities of daily living and level of behavioral problems with care recipient were found to influence most to their quality of relationship. Gender and relationship (spouse, child ext) may influence also to quality of relationship. Study recommends to gain more understanding of the role of relationship in caregiving to develop better interventions that have an effect on well-being of both caregivers and care-recipients. LIke.</td>
</tr>
<tr>
<td>Reference</td>
<td>Title</td>
<td>Methodology</td>
<td>Participants</td>
<td>Findings</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>-------</td>
<td>-------------</td>
<td>--------------</td>
<td>----------</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Holst and Edberg, (2011)</td>
<td>Wellbeing among people with dementia and their next of kin over a period of 3 years</td>
<td>Quantitative</td>
<td>Data consisted of patient self-reports, assessments made by nurses and next to kin's self-reports</td>
<td>Logistic regression analysis was used</td>
<td>In the period of 3 years time it came evident that inter-relationship between person with dementia mood and next to kin's satisfaction and burden seem to get stronger over time (E). Next to kin's burden was related to health (P) and problem behaviour of PWD. (O)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Gaugler, Kane, and Newcomer (2007)</td>
<td>Resilience and Transition From Dementia Caregiving</td>
<td>Quantitative</td>
<td>Data from 1979 caregivers over 3-year period</td>
<td>Multinomial logistic regression models were used</td>
<td>High baseline resilience (P) (low burden, high care demands) was associated with less frequent institutionalization and loss to follow-up as well as more frequent care recipient mortality.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Merrick, Camic, and O’Shaughnessy, (2016)</td>
<td>Couples constructing their experiences of dementia: A relational perspective</td>
<td>Qualitative</td>
<td>Interviews were done of the couples</td>
<td>The situation of interviewing could cause stress, Couples who are doing well participate more easily, Only one time interviewing, no temporal dimension</td>
<td>Findings recommend further development of personification models to support that take both’s situation and experience into account.</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Giebel and Sutcliffe (2018)</td>
<td>Initiating activities of daily living contributes to</td>
<td>Quantitative</td>
<td>Data were analysed using correlation analysis</td>
<td>Categorisation of people</td>
<td>Findings suggest improving care management early in the disease. (O) Findings emphasized to provide more social groups (E) and engaging individual hobbies (O) and activities (O) to improve both of dyads well-being. (E)(O)</td>
<td>Deficits in IADL (O), like reminding, monitoring the day and dressing were found to be to most distressing activities. Effective triggers and reminders are recommended.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ID</td>
<td>Authors</td>
<td>Journal</td>
<td>Key Concepts</td>
<td>Methodology</td>
<td>Findings</td>
<td>Suggestions</td>
<td></td>
<td></td>
</tr>
<tr>
<td>----</td>
<td>---------</td>
<td>---------</td>
<td>--------------</td>
<td>-------------</td>
<td>----------</td>
<td>-------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>46</td>
<td>Soilemezi, Drahota, Crossland, Stores and Costall</td>
<td>International Journal of Geriatric Psychiatry</td>
<td>Well-being in people with dementia and their carers</td>
<td>Exploring the meaning of home for family caregivers of people with dementia</td>
<td>Qualitative thematic analysis by interviews and observing home</td>
<td>The findings revealed that ‘home is everything’ for caregivers. Two major themes with two sub-themes were found. 1. The different meanings of home: 1.1 home as a secure haven, and 1.2 home looks like a hospital, feels like as a prison (E) 2. Perceived impact of home: to move or not to move? 2.1 need for relocation, and 2.2 staying in place but redefine the home environment. (E) Suggestions: Escape room (E) for caregiver to settle down and for hobbies (O). Alert architects and home designers of possibility of the role of home when caregiving and abilities also for privacy and home to feel as home also with assistive devices</td>
<td></td>
<td></td>
</tr>
<tr>
<td>47</td>
<td>Deist, Greeff</td>
<td>Educational Gerontology</td>
<td>Resilience in Families</td>
<td>Exploring aspects associated with family resilience in families caring for a demented family member</td>
<td>Mixed method approach using a structured questionnaire and semi structured interview</td>
<td>Family adaptation had a strong and statistically significant positive correlation with communication (problem-solving and affirming and supporting) (E) (OP) Results could be used to develop interventions to create family environments that improves adjustment and adaptation.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Notes:**
- E: Evidence-based
- O: Original research
Appendix. Journal information

Scandinavian Journal of Occupational Therapy

Instructions for authors
Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

Contents

- About the Journal
- Peer Review
- Preparing Your Paper
- Style Guidelines
- Formatting and Templates
- References
- Checklist
- Using Third-Party Material
- Disclosure Statement
- Clinical Trials Registry
- Complying With Ethics of Experimentation
- Consent
- Health and Safety
- Submitting Your Paper
- Data Sharing Policy
- Publication Charges
- Copyright Options
- Complying with Funding Agencies
- Open Access
- My Authored Works
- Reprints
About the Journal

_Scandinavian Journal of Occupational Therapy_ is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

_Scandinavian Journal of Occupational Therapy_ accepts the following types of article:

- Original Articles
- Case Reports
- Reviews
- Letters to the Editor
- Short Communications

Peer Review

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing Your Paper

All authors submitting to medicine, biomedicine, health sciences, allied and public health journals should conform to the *Uniform Requirements for Manuscripts Submitted to Biomedical Journals*, prepared by the International Committee of Medical Journal Editors (ICMJE).

Submissions should add to already published papers. Please ensure your writing is concise.

Original Articles, Case Reports and Reviews

- Should be written with the following elements in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; Methodological considerations / limitations; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)
- An average article should be around 5000 words, but can be up to a maximum of 8500 words.
- Should contain a structured abstract of 200 words. Background, Aims/Objectives, Material and Methods, Results, Conclusions and Significance.
- Between 3 and 10 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization. - The introduction should explain the background of the study grounded in updated literature. The rationale of study
should be stated and the significance for occupational therapy explained. The aim of the study should be clearly described.

- The **material and methods** section should give sufficient detail to enable other investigators to repeat the work. Describe new methods in detail. The design and investigated population should be appropriate for the research problem stated and aim of the study. Consider reliability/validity or trustworthiness of the instruments and procedures. Use appropriate statistical and qualitative analyses and procedures. Ethical considerations should be accounted for.

- The **results** section should be concise and focus on findings relevant to the aim of the study. When relevant, use pertinent quotations as illustrations to qualitative findings. Figures and tables should be adequately annotated and enhancing the presentation of material. Avoid presenting data in more than one form.

- The **discussion** section should give critical assessment of the results of the study in view of previously reported research. Conclusions in relation to the aim should be stated likewise the significance of findings for occupational therapy. Avenues for future research should be suggested. Methodological considerations/limitations should be acknowledged.

- **Acknowledgments** - State funding and sources of support in the form of e.g. grants or equipment on a separate Acknowledgements page.

- A **cover letter** should be provided, where authors vouch for the accuracy of the manuscript according to the guidelines given here. This is also the place where authors may inform the Editors of any special circumstances or details regarding the submitted material, including prior publication of the material/parts of the material in a minority language.

- The author should always make a full statement to the editor about all submissions and previous reports that might be regarded as redundant or duplicate publication of the same or very similar work.

- For **review articles**, authors are requested to discuss the topic of the proposed review with the Editor-in-Chief before submission.

**Letters to the Editor**

- Should be written with the following elements in the following order: title page; keywords; main text; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)

**Short Communications**

- Should be written with the following elements in the following order: title page; introduction; main text; results; discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list)

- An average Short Communication should be around 2700 words.

**Style Guidelines**

Please refer to these **quick style guidelines** when preparing your paper, rather than any published articles or a sample copy.
Please use British (-ise) spelling style consistently throughout your manuscript.

Please use single quotation marks, except where ‘a quotation is “within” a quotation’. Please note that long quotations should be indented without quotation marks.

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

If you are not able to use the template via the links (or if you have any other template queries) please contact authortemplate@tandf.co.uk.

If you choose not to use a word template for submission, the text should be double-spaced with generous margins. Times New Roman in 12 pt size is the preferred font style. Smaller spacing and font may be used for references, tables and figure legends.

Please be consistent. The same elements should be keyed in exactly the same way throughout the manuscript. Do not break words at the end of lines. Use a hyphen only to hyphenate compound words. Enter only one space after the full-stop at the end of a sentence. When emphasizing words, please use the italic feature of your word processor software. Do not justify your text; use a ragged right-hand margin.

Use a double hyphen (--) to indicate a dash in text. Do not use the lowercase I for 1 (one) or the uppercase O for 0 (zero). The space bar should only be used as a word separator. Use TAB when indenting paragraphs or separating columns in tables Graphic elements and illustrations are accepted if providing unique data that can not be described in the text, and should be clearly marked with Arabic numbers as they appear in the text.

To ensure correct placement in the journal layout, note the figure reference (abbreviated) within brackets when referring to the figure in text, e.g. (Fig. 1).

Language

It is the responsibility of authors to ensure the quality of the language for submitted articles. Colloquial English may not be sufficient and is not necessarily the same as scientific English, for which professional services may be needed (see for example http://www.tandfeditionservices.com/en/). A brief language overview will be made for articles accepted for publication, but no major changes are accepted at this stage.

Statistic validity

If statistical data is provided, authors are requested to submit an official statement issued by a certified statistician (with a proper affiliation) regarding the validity of methods used.

References
Please use this reference guide when preparing your paper. Detailed examples are available on the reference guide.

An EndNote output style is also available to assist you.

Checklist: What to Include

1. **Author details.** Please ensure everyone meeting the International Committee of Medical Journal Editors (ICJME) requirements for authorship is included as an author of your paper. All authors of a manuscript should include their full name and affiliation on the cover page of the manuscript. Where available, please also include ORCiDs and social media handles (Facebook, Twitter or LinkedIn). One author will need to be identified as the corresponding author, with their email address normally displayed in the article PDF (depending on the journal) and the online article. Authors’ affiliations are the affiliations where the research was conducted. If any of the named co-authors moves affiliation during the peer-review process, the new affiliation can be given as a footnote. Please note that no changes to affiliation can be made after your paper is accepted. Read more on authorship.

2. You can opt to include a **video abstract** with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.

3. **Funding details.** Please supply all details required by your funding and grant-awarding bodies as follows:
   - **For single agency grants**
     This work was supported by the [Funding Agency] under Grant [number xxxx].
   - **For multiple agency grants**
     This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

4. **Disclosure statement.** This is to acknowledge any financial interest or benefit that has arisen from the direct applications of your research. Further guidance on what is a conflict of interest and how to disclose it.

5. **Data availability statement.** If there is a data set associated with the paper, please provide information about where the data supporting the results or analyses presented in the paper can be found. Where applicable, this should include the hyperlink, DOI or other persistent identifier associated with the data set(s). Templates are also available to support authors.

6. **Data deposition.** If you choose to share or make the data underlying the study open, please deposit your data in a recognized data repository prior to or at the time of submission. You will be asked to provide the DOI, pre-reserved DOI, or other persistent identifier for the data set.

7. **Supplemental online material.** Supplemental material can be a video, dataset, fileset, sound file or anything which supports (and is pertinent to) your paper. We publish supplemental material online via Figshare. Find out more about supplemental material and how to submit it with your article.

8. **Figures.** Figures should be high quality (1200 dpi for line art, 600 dpi for grayscale and 300 dpi for colour, at the correct size). Figures should be supplied in one of our preferred file formats: EPS, PS, JPEG, GIF, or Microsoft Word (DOC or DOCX). For information relating to other file types, please consult our Submission of electronic artwork document.

9. **Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.
10. **Equations.** If you are submitting your manuscript as a Word document, please ensure that equations are editable. More information about mathematical symbols and equations.

11. **Units.** Please use SI units (non-italicized).

### Using Third-Party Material in your Paper

You must obtain the necessary permission to reuse third-party material in your article. The use of short extracts of text and some other types of material is usually permitted, on a limited basis, for the purposes of criticism and review without securing formal permission. If you wish to include any material in your paper for which you do not hold copyright, and which is not covered by this informal agreement, you will need to obtain written permission from the copyright owner prior to submission. More information on requesting permission to reproduce work(s) under copyright.

### Disclosure Statement

Please include a disclosure statement, using the subheading “Disclosure of interest.” If you have no interests to declare, please state this (suggested wording: *The authors report no conflict of interest*). For all NIH/Wellcome-funded papers, the grant number(s) must be included in the declaration of interest statement. Read more on declaring conflicts of interest.

### Clinical Trials Registry

In order to be published in a Taylor & Francis journal, all clinical trials must have been registered in a public repository at the beginning of the research process (prior to patient enrolment). Trial registration numbers should be included in the abstract, with full details in the methods section. The registry should be publicly accessible (at no charge), open to all prospective registrants, and managed by a not-for-profit organization. For a list of registries that meet these requirements, please visit the WHO International Clinical Trials Registry Platform (ICTRP). The registration of all clinical trials facilitates the sharing of information among clinicians, researchers, and patients, enhances public confidence in research, and is in accordance with the ICMJE guidelines.

### Complying With Ethics of Experimentation

Please ensure that all research reported in submitted papers has been conducted in an ethical and responsible manner, and is in full compliance with all relevant codes of experimentation and legislation. All papers which report in vivo experiments or clinical trials on humans or animals must include a written statement in the Methods section. This should explain that all work was conducted with the formal approval of the local human subject or animal care committees (institutional and national), and that clinical trials have been registered as legislation requires. Authors who do not have formal ethics review committees should include a statement that their study follows the principles of the Declaration of Helsinki.

### Consent
All authors are required to follow the ICMJE requirements on privacy and informed consent from patients and study participants. Please confirm that any patient, service user, or participant (or that person’s parent or legal guardian) in any research, experiment, or clinical trial described in your paper has given written consent to the inclusion of material pertaining to themselves, that they acknowledge that they cannot be identified via the paper; and that you have fully anonymized them. Where someone is deceased, please ensure you have written consent from the family or estate. Authors may use this Patient Consent Form, which should be completed, saved, and sent to the journal if requested.

Health and Safety

Please confirm that all mandatory laboratory health and safety procedures have been complied with in the course of conducting any experimental work reported in your paper. Please ensure your paper contains all appropriate warnings on any hazards that may be involved in carrying out the experiments or procedures you have described, or that may be involved in instructions, materials, or formulae.

Please include all relevant safety precautions; and cite any accepted standard or code of practice. Authors working in animal science may find it useful to consult the International Association of Veterinary Editors’ Consensus Author Guidelines on Animal Ethics and Welfare and Guidelines for the Treatment of Animals in Behavioural Research and Teaching. When a product has not yet been approved by an appropriate regulatory body for the use described in your paper, please specify this, or that the product is still investigational.

Submitting Your Paper

This journal uses ScholarOne Manuscripts to manage the peer-review process. If you haven’t submitted a paper to this journal before, you will need to create an account in ScholarOne. Please read the guidelines above and then submit your paper in the relevant Author Centre, where you will find user guides and a helpdesk.

Please note that Scandinavian Journal of Occupational Therapy uses Crossref™ to screen papers for unoriginal material. By submitting your paper to Scandinavian Journal of Occupational Therapy you are agreeing to originality checks during the peer-review and production processes.

On acceptance, we recommend that you keep a copy of your Accepted Manuscript. Find out more about sharing your work.

Data Sharing Policy

This journal applies the Taylor & Francis Basic Data Sharing Policy. Authors are encouraged to share or make open the data supporting the results or analyses presented in their paper where this does not violate the protection of human subjects or other valid privacy or security concerns.

Authors are encouraged to deposit the dataset(s) in a recognized data repository that can mint a persistent digital identifier, preferably a digital object identifier (DOI) and recognizes
a long-term preservation plan. If you are uncertain about where to deposit your data, please see this information regarding repositories.

Authors are further encouraged to cite any data sets referenced in the article and provide a Data Availability Statement.

At the point of submission, you will be asked if there is a data set associated with the paper. If you reply yes, you will be asked to provide the DOI, pre-registered DOI, hyperlink, or other persistent identifier associated with the data set(s). If you have selected to provide a pre-registered DOI, please be prepared to share the reviewer URL associated with your data deposit, upon request by reviewers.

Where one or multiple data sets are associated with a manuscript, these are not formally peer reviewed as a part of the journal submission process. It is the author’s responsibility to ensure the soundness of data. Any errors in the data rest solely with the producers of the data set(s).

**Publication Charges**

There are no submission fees or page charges for this journal.

Colour figures will be reproduced in colour in your online article free of charge. If it is necessary for the figures to be reproduced in colour in the print version, a charge will apply.

Charges for colour figures in print are £300 per figure ($400 US Dollars; $500 Australian Dollars; €350). For more than 4 colour figures, figures 5 and above will be charged at £50 per figure ($75 US Dollars; $100 Australian Dollars; €65). Depending on your location, these charges may be subject to local taxes.

**Copyright Options**

Copyright allows you to protect your original material, and stop others from using your work without your permission. Taylor & Francis offers a number of different license and reuse options, including Creative Commons licenses when publishing open access. Read more on publishing agreements.

Please note that authors have the right to use their own material in thesis work without further permission from Taylor & Francis.

**Complying with Funding Agencies**

We will deposit all National Institutes of Health or Wellcome Trust-funded papers into PubMedCentral on behalf of authors, meeting the requirements of their respective open access policies. If this applies to you, please tell our production team when you receive your article proofs, so we can do this for you. Check funders’ open access policy mandates here. Find out more about sharing your work.
Open Access

This journal gives authors the option to publish open access via our Open Select publishing program, making it free to access online immediately on publication. Many funders mandate publishing your research open access; you can check open access funder policies and mandates here.

Taylor & Francis Open Select gives you, your institution or funder the option of paying an article publishing charge (APC) to make an article open access. Please contact openaccess@tandf.co.uk if you would like to find out more, or go to our Author Services website.

For more information on license options, embargo periods and APCs for this journal please go here.

My Authored Works

On publication, you will be able to view, download and check your article’s metrics (downloads, citations and Altmetric data) via My Authored Works on Taylor & Francis Online. This is where you can access every article you have published with us, as well as your free eprints link, so you can quickly and easily share your work with friends and colleagues.

We are committed to promoting and increasing the visibility of your article. Here are some tips and ideas on how you can work with us to promote your research.

Article Reprints

You will be sent a link to order article reprints via your account in our production system. For enquiries about reprints, please contact the Taylor & Francis Author Services team at reprints@tandf.co.uk. You can also order print copies of the journal issue in which your article appears.

Queries

Should you have any queries, please visit our Author Services website or contact us at authorqueries@tandf.co.uk