

SUPPORTING OLDER ADULTS WITH CHEMOTHERAPY TREATMENT: A MIXED  
METHODS EXPLORATION OF CANCER CAREGIVERS' EXPERIENCES AND  
OUTCOMES

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## *ABSTRACT*

**Purpose:** Due to delivery of chemotherapy being mostly in ambulatory care settings, support of people with cancer relies heavily on caregivers (e.g. relatives). Whilst cancer caregiver research has been flourishing, there has been little focus on the specific experiences of caregivers of older people (>70yrs) with cancer, and little considerations of cultural influences on their experiences. This study explored caregiver experiences and outcomes in the geriatric oncology context in Switzerland.

**Methods:** Sequential mixed-methods design, comprising a) cross-sectional survey ( $n=86$ /RR52%; age range 37-85) and b) interviews ( $n=19$ ) to explore experiences of caregivers of older people (mean age in yrs 74.6 ( $sd$  4.3) with cancer, and factors related to caregivers' psychological morbidity and health related quality of life (HrQoL).

**Results:** Caregivers reported a median of three moderate/high unmet needs (range 0–41) and 44% reported clinically significant psychological morbidity. Demographics (caregiver age, gender, and marital status), caregiving tasks (physical, psycho-emotional, social and/or treatment related care), unmet needs and caregiver burden collectively explained between 20-57% of variance in caregiver psychological morbidity and HRQoL. Two main themes emerged from interviews: "Being a caregiver and doing caregiving" and "Living through the situation." These indicated that caregiver roles are multiple and fluid, and identified responsibilities not previously reported outside of palliative care settings, such as thinking about and planning for death and dying.

**Conclusions:** Caregiving for an older person with cancer can have detrimental impacts on caregivers' wellbeing and quality of life. Consideration needs to be given to the particular needs of caregivers in geriatric oncology settings. Their support needs appear different to those of their counterparts caring for younger people with cancer, notably related to spiritual needs; this may in part relate to possible differences arising from caregivers themselves being older.

## *KEY WORDS*

Cancer caregivers, older adults, chemotherapy, experiences, needs, geriatric oncology

## *INTRODUCTION*

Adult cancer patients are predominantly supported through their illness and treatment by caregivers (e.g. partners, relatives and friends). Research with cancer caregivers has explored different aspects of their experiences, often aligned conceptually with stress-process frameworks (Stenberg et al., 2010). Experiences reported by caregivers include psychological distress and caregiver burden; gender, psycho-social resources and other factors have been identified as shaping these experiences (Fletcher et al., 2012, Li et al., 2013, Northouse et al., 2012, Hagedoorn et al., 2008, Stenberg et al., 2010). Evidence suggests that caregiver burden within cancer care is generally moderate to high; carers report reduced quality of life (Kitrungrote and Cohen, 2006, Creswell and Plano Clark, 2011) and unmet needs for support (Deeken et al., 2003, Sklenarova et al., 2015b, Girgis et al., 2010). Top unmet needs are purported to include adequate hospital parking, support with concerns about disease recurrence, information about disease and treatment, and access to high quality services for their relative/friend with cancer (Girgis et al., 2010, Ream, 2013, Turner et al., 2013, Girgis et al., 2013). Recently, the spiritual dimensions of caregivers' experience and wellbeing have been reported on (Colgrove et al., 2007, Kim et al., 2015, Tan et al., 2015), although findings are inconsistent. In one study, spiritual wellbeing was found to vary by gender (higher in female caregivers) (Kim et al., 2015), whereas Colgrove et al. found that higher spiritual wellbeing was associated with better mental health-related quality of life and that it was independent of gender. Cancer patients' ability to derive meaning from their illness was reported to have a positive impact on their caregivers' spiritual wellbeing (Tan et al., 2015).

As the proportion of older adults with cancer is rising, increasing numbers of caregivers are supporting an older person with cancer. Cancer care for older adults has to address distinct challenges based on biological and psychosocial factors relating to being older - such as increased frailty due to living with higher numbers of comorbidities, poly-pharmacy and geriatric syndromes (Wildiers et al., 2014). Consequently, caregivers of older adults with cancer are likely to face distinct experiences and may also be older themselves. However, research on the experiences and needs of cancer caregivers when supporting patients of 70+ years is limited (Van Cleave et al., 2016). It is not known if/how co-morbidities of the person with cancer impact on caregivers' experiences; whether they take on different types/amounts of caregiving tasks compared to caregivers of younger adult cancer patients, and how the caregiver role impacts them emotionally and physically or affects their quality of life (Sklenarova et al., 2015a, Janda et al., 2008, Girgis et al., 2010, Girgis et al., 2013, Glajchen, 2012). There is limited evidence concerning how caregiver needs vary with patients' age or treatment modality (Ream, 2013). Thus, the purpose of the current study was to explore and describe the experiences, needs and outcomes of caregivers of older

people (age  $\geq 70$  years) with cancer having ambulatory chemotherapy in order to address shortfalls in current evidence.

## *METHODS*

### Study Design

A conceptual framework (Figure 1), developed from the literature on cancer caregiving, caregiving in the geriatric context and the stress process theory (Pearlin et al., 1990), informed the study design. A sequential mixed-methods design, of the participant selection sub-type, was employed (Creswell and Plano Clark, 2011). Phase 1 was a quantitative survey. Phase 2 comprised a qualitative face-to-face interview study conducted with a purposefully selected subsample of Phase 1 participants. Both phases produced equally weighted data sets and were analysed separately before being integrated (O'Cathain et al., 2010).

### Study Sites and Participants

Caregivers were recruited at one of three outpatient chemotherapy clinics in the north-eastern German-speaking part of Switzerland. During the recruitment phase, all patients  $\geq 70$  years of age having started chemotherapy within the previous 4-8 weeks at the three sites were asked by a trained on-site staff nurse for permission to approach their caregiver to participate in the research (April 2011 to June 2012). Named caregivers were then sent information about the study within the Phase 1 survey pack. Consent was implied by anonymous return of the survey, in a pre-paid envelope, to the university-based study manager; caregivers could include their contact details if they were interested in Phase 2 participation. Caregivers for Phase 2 interviews were purposefully selected from those providing their contact details using a sampling frame considering gender (female/male), relationship type with the older person with cancer (spouse/partner or adult child) and level of unmet needs reported in the survey (low or high).

### Phase 1: Cross-sectional Survey

The survey addressed the question: what are the consequences (and associated factors) of caregiving for older adults with cancer (70+ years of age) during ambulatory chemotherapy treatment? The hypothesised relationship between caregiving and outcomes was underpinned conceptually by the stress-process theory (Fig.1) (Pearlin et al., 1990).

### Measurements

The survey contained five sections and would take about 20-30 min to complete. The first section contained questions regarding socio-demographics including caregiver gender,

relationship type to the person with cancer (e.g. spouse/partner; child), age, marital status, employment status, income, and living situation. Relationship quality was measured with the 12 item Mutuality scale of the Family Care Inventory (Archbold et al., 1990). In the next section, due to the absence of appropriate validated tools, the type and frequency of caregiving tasks was assessed using a study-specific measure that assessed support across four domains: psycho-emotional support, physical support, support in social/daily life activities and support in disease/treatment; with frequency reported on a 4 point Likert scale (never, seldom, sometimes or always). In section 3, type and frequency of caregiver needs were measured with the 44-item Supportive Care Needs Survey for Partner and Caregiver Scale (SCNS – P&C)(Girgis et al., 2010). In section 4, the 24 item Caregiver Reaction Assessment (CRA) (Given et al., 1992) was used to assess burden/benefit of caregiving in five subscales, i.e. caregiver esteem, health, finance, family support and change to schedule. The twelve item Functional Assessment of Chronic Illness Therapy – Spiritual Well-Being Scale (FACIT –Sp12) (Peterman et al., 2002) assessed spiritual wellbeing as an additional potential benefit of caregiving. The final section assessed health related quality of life and psychosocial morbidity were with the SF-12 Health Survey (Ware et al., 1996) and the General Health Questionnaire-12-item short form (GHQ12)(Goldberg et al., 1997). All instruments have previous robust validity and reliability data reported within the cancer care setting (Girgis et al., 2010, Bullinger and Kirchberger, 1998, Peterman et al., 2002, Goldberg et al., 1997, Archbold et al., 1990, Given et al., 1992).

## Analysis

Bivariate relationships between nominal/ordinal variables were explored using cross tabulations, chi-square tests and Mann-Whitney-U or Kruskal-Wallis-test. Relationships between continuous variables were explored through calculating Spearman's Rank correlation co-efficient. For a regression study with eight predictors, with an anticipated effect size ( $f^2$ ) of 0.2, power of 0.8, and probability level at 0.05, a sample of 83 participants was required. Before multiple regression analysis, assumptions for the test were evaluated. Hierarchical regression analysis was performed for model fit and exploration of the final models (Polit, 2010, Tabachnick and Fidell, 2001).

## Phase 2: Qualitative Interviews

To expand exploration of caregivers' experiences, this phase sought to answer the question: How do caregivers experience caregiving during older patients' treatment with chemotherapy?

## Data Collection and Analysis

Face to face semi-structured interviews (mean=45min; range 28-80min) were carried out by the first author, following a topic guide based on study aims and the conceptual framework (Figure 1). Interviews were audio recorded after receipt of written informed consent. After verbatim transcription, data were managed and analysed using the Framework approach (Ritchie et al., 2009). The central component of this approach is the development of matrices, based on the thematic framework developed in an early stage of the analysis; this allows iterative development of concepts and examination of patterns in the data both within and between cases (e.g. comparing themes between different relationship types of caregivers).

## Data Integration

Data from both phases were integrated using mixed methods matrices to compare and contrast findings (O'Cathain et al., 2010). Moffatt et al.'s (2006) six-step approach was used to explore any conflicting results that emerged. This method encourages exploration of six potential reasons for conflict: (1) treating the methods as fundamentally different; (2) exploring the methodological rigour of each component; (3) exploring dataset comparability; (4) collecting further data and making further comparisons; (5) exploring the process of the intervention; and/or (6) exploring whether the outcomes of the two components match (Moffatt et al., 2006). Two of these, (4) and (5), were not applicable in this study. Collecting more data to make further comparisons was not possible due to time constraints and limited scope of a doctoral study and exploration of the intervention process did not apply to this observational study.

## RESULTS

A total of 206 eligible patients were approached in the recruitment period, resulting in 165 caregivers being sent an information pack and Phase 1 survey. Of these, fifty-two (61%) female and 34 (39%) male caregivers completed the survey (RR52%), and 19 were selected for participation in Phase 2. The mean age of the sample was 65.3 years (*sd* 13.7; range 37-85), however, the distribution was bifurcated. Spouse/partner caregivers (mean age of 73.4, *sd* 5.4) were all over 60 years of age versus adult children/children-in-law (mean age of 46.5, *sd* 5.7) being all under 60 years of age. On further examination, this distribution paralleled, by and large, the relationship type as well as employment status. Only three of the over 60 year old caregivers were in paid employment and only one adult child caregiver reported to be unemployed. The socio-demographic characteristics for the overall caregiver sample are presented in Table 1.

Just over half of the older adults with cancer whose caregivers participated in the study were female ( $n = 48, 56\%$ ) and 38 (44%) were male. The mean age of the older person with cancer was 74.6 ( $SD 4.3$ ; range 70-89) years.

## Phase 1 Results

### Descriptive and Bivariate Analysis

The highest level of caregiver burden was in the area of “changes to schedule” (Table 1). Female gender, lower yearly income and being married were personal characteristics related to higher “change of schedule” scores (all  $p \leq 0.02$ ). Female gender was also associated with higher scores on the CRA “health” subscale ( $MWU: 45.9$  vs  $31.6; p = 0.01$ ). Spousal caregivers reported less negative consequences and higher gains in all CRA subscales except “lack of family support”, compared to adult children caregivers (all  $p < 0.05$ ). Relationship quality was weakly to moderately associated with spiritual wellbeing and all five CRA sub-scales ( $r = 0.37-0.53; p \leq 0.001$ ). The main needs that caregivers reported were health care service and information needs (Table 2). Female caregivers reported more unmet needs than male caregivers ( $MWU 48.9$  vs  $35.3; p = 0.01$ ).

With a cut off score  $GHQ12 \geq 11$  (Goldberg et al., 1997), a clinically significant level of psychological morbidity was reported by 37% of the spouses and 64% of the adult children caregivers. Compared to adult children caregivers, spouse caregivers reported better mental health related quality of life ( $MWU 45.8$  vs  $31.1; p = 0.01$ ) but, not surprisingly given their older age, worse physical health related quality of life ( $MWU 36.1$  vs  $54.6; p = 0.001$ ). Relationship type, relationship quality and gender were significantly associated with caregivers’ psychological morbidity and mental health related quality of life (all  $p \leq 0.003$ ), with spouse caregivers, male caregivers and caregivers with better perceived relationship quality reporting better outcomes.

### Predictors of Psychological Morbidity

Spiritual wellbeing scores contributed the most ( $\beta = -.332, p = 0.001$ ) to the predictive value of the model (higher scores related to less psychological morbidity). Having lower total caregiving task frequency ( $\beta = 0.214, p = 0.01$ ), less health burden ( $\beta = 0.306, p = 0.009$ ), and less unmet needs ( $\beta = .220, p = 0.009$ ) all independently contributed to better psychological outcomes (Table 3). Adjusted variance of 13% ( $R^2 = .181, F(4,73) = 3.813; p \leq 0.007$ ) in caregiver psychological morbidity was explained by caregiver age, gender, marital status and relationship quality. Once caregiver experience variables were added the total adjusted variance explained increased to 57% ( $R^2 = .618, F(8,69) = 9.677; p \leq 0.001$ ).

## Predictors of Mental and Physical Health related Quality of Life

The strongest predictor for higher mental health related quality of life (MQ) was better spiritual wellbeing ( $\beta = .298, p=0.005$ ). Being married ( $\beta = .285, p=0.003$ ), having less health burden ( $\beta = -.269, p=0.039$ ) and less change to schedule ( $\beta = -.246, p=0.038$ ) were also independent predictors in the final model. Younger age, less health burden and better family support were statistically significant predictors of better physical health related quality of life (PQ), with health burden being the strongest independent predictor ( $\beta = -.539, p<0.001$ ). The total adjusted variance explained by the model after controlling for demographic variables was 37% for the physical health related quality of life (PQ), and 53% for the mental health related quality of life (MQ).

## Phase 2 Findings

The group of 19 caregivers in Phase 2 were made up of seven male partner/spouses and twelve women of whom four were adult daughters. Overall, the socio-demographic and caregiver outcome characteristics of this group were comparable to the overall Phase 1 sample. Although no clinical disease stage characteristics pertaining to the older person with cancer the caregivers looked after was collected, information obtained in the interviews indicated that a third of the Phase 2 caregivers ( $n=7$ ) were supporting an older person with advanced disease (defined by the caregiver mentioning either mentioning metastatic and/or recurrent disease). The two main themes that emerged in the interview data were: "Being a caregiver and doing caregiving", and "Living through the situation". Each theme had two subthemes and exemplary illustrative quotations are provided in Tables 4 and 5.

### Being a caregiver and doing caregiving

Four distinct but overlapping caregiver roles were identified: partner/companion, expert carer/lay therapist, advocate, and protector. Caregivers would move from one role to another in a fluid way, and caregiving tasks were not assigned to any caregiver role in a mutually exclusive fashion. Enacting the four roles, caregivers would engage in a range of caregiving activities, e.g. giving psycho-emotional support, giving support in relation to disease and treatment management and managing everyday social life. A caregiving activity articulated by several caregivers that was not mentioned in previously reported caregiving task typologies was the activity of "thinking about and planning for death and dying". The older age of the person with cancer in and of itself appeared to be the most prominent stimulus for reflecting on the theme of death and/or engaging with the care task of thinking about and planning for death/dying.



Four factors were identified that appeared to influence what type of role a caregiver would engage in and/or what caregiving activity they would take on. Previous relationship patterns and/or family dynamics, as well as characteristics of the older person with cancer, in particular their health status, were two factors that contributed often to what caregivers did on behalf of and for the person with cancer they were supporting through chemotherapy. Mentioned somewhat less often, personal reflection on older age in general and/or on being old, as well as preconceived role expectation were two further factors that appeared to influence role acquisition and caregiving responsibilities.

#### Living through the situation

The varied caregiver roles and associated tasks had different impacts on caregivers as they lived through the day to day of caregiving. Consequences of caregiving were identified in relation to caregivers' psycho-emotional, physical, social and spiritual wellbeing. Changes to everyday life patterns encompassed not only diminishing/cessation of previous activities but also an increase, or uptake of new activities. Various needs emerged as a consequence of being a caregiver. These included health care service needs, information needs, psycho-spiritual-social needs and needs related to finance, employment or legal matters. Rewarding consequences were not often recounted. Most of the consequences reported by caregivers were potentially deleterious to some aspects of the caregiver's wellbeing, and all interviewed caregivers discussed some negative impacts with respect to caregiving.

#### *DATA INTEGRATION*

There was congruence between the two datasets in relation to many of the findings, particularly regarding relationships between caregiving and gender, relationship type and/or level of needs:

1. No male caregivers in this study assumed the protector role, and a tendency was observed for caregivers with higher levels of need to not as readily enact the advocate role;
2. Only female caregivers voiced feelings of being valued in their role, being thanked for or receiving gratitude for what they do as caregivers, experiencing positive emotions through closeness or gaining valuable life experience;
3. Negative health consequences were reported more by the female caregivers, and almost all female caregivers experienced some detrimental changes in relationship patterns associated with their caregiver role, in comparison to less than half of the male caregivers articulating this;
4. Female caregivers, caregivers with higher unmet needs and caregivers of older people with advanced disease were more likely to talk about consequences within the domain of spiritual wellbeing;

5. Whereas male caregivers were offered what they often felt was unnecessary support for household chores, some female caregivers had unmet needs in this regard.

6. Psycho-spiritual-social needs appeared more prominent in female caregivers and caregivers with high levels of need, whereas needs of a financial or employment related nature were more often articulated by caregivers of older people with advanced disease.

When integrating findings, only one instance of conflict between the datasets was identified. This concerned whether gender was associated with experience of positive consequences of caregiving. In Phase 1 gender was not associated with either self-esteem or spiritual wellbeing, but in Phase 2 only female participants voiced positive experiences of caregiving. Using Moffatt et al.'s (2006) framework this discrepancy could be explained by the differences in measurement between the quantitative vs qualitative approach. Thus, this difference likely exemplifies one aspect of data triangulation, understood as shining two lights from different vantage points onto an object, with each light potentially illuminating part of the object that are left in the dark by the rays of the other light (Creswell and Plano Clark, 2011, Moffatt et al., 2006, O'Cathain et al., 2010).

## *DISCUSSION*

This study explored the experiences and consequences of caregiving for older cancer patients during chemotherapy treatment. It generated some distinct findings related to the specific population and setting, alongside others that resonate with those reported previously in research with caregivers of younger adult cancer patients. Caregiver role characteristics have been described earlier (McIlfatrick et al., 2006), but our identification of fluidity between different caregiver role characteristics provides new and distinct understanding of the situational complexity that caregivers of older people with cancer find themselves in, and the associations between role characteristics and caregiver activities.

“Talking about and planning for death and dying” was a unique finding in this study, and a frequent caregiving activity that caregivers of older people with cancer described in their role as partner and advocate. One previous study had reported a similar theme: ‘preparing for leave-taking’ in a study by (Esbensen and Thomé, 2010). In their study, participants recounted how they were being made acutely aware of the older person’s approaching death, often associated with the older age of the person with cancer. This led to caregivers’ thoughts about their own future and how it would be to live as a widow/er, which is similar to accounts of some caregivers given in the current study. However, the current study builds on this by encompassing the impact of caregiver’s thoughts about the future on their relationship with the older person with cancer, and their role in talking to them and planning for death and dying. This caregiving activity was described often in the current study, despite many of the older people with cancer being treated with curative intent, with more recent

evidence pointing at a lack of advanced care planning support from health professionals in this regard (Hopkins et al., 2020).

Congruent with previous studies of caregivers, we found higher levels of burden and lower quality of life than in the general population (Stenberg et al., 2010). In the areas of health, finance, change of schedule, self-esteem and spiritual wellbeing; adult children caregivers reported more detrimental consequences than the older spouse/partner caregivers in the current study. These results conflict with findings of a comprehensive review by Pinguart and Sørensen (2011), summarising impact of caregiving to older frail adults in the community setting who found older caregivers (i.e. partners/spouses) to be more negatively impacted than the younger (i.e. adult children) cohort. The difference in results could be attributed to the better overall health status of the older adults with cancer in our study compared with the frail older adults in Pinguart and Sørensen's review who likely needed much more physical care support. This may have protected the caregiver of the older adults in this study from detrimental effects reported previously.

Caregivers in this study either implied or explicitly discussed a large array of needs and reported a median of three moderately/highly unmet needs in the survey. This rate of unmet need is similar to that reported by other caregiver research of cancer patients of younger age and/or different treatment modalities internationally (Sanson-Fisher et al., 2000, Janda et al., 2008, Armoogum et al., 2013, Sklenarova et al., 2015a, Girgis et al., 2010, Heckel et al., 2016). Compared to previous studies, there were differences in the type of prevalent needs in our sample, although the rate of unmet needs was similar. Factors that could account for these differences - in addition to patients' age, disease type, stage and treatment – include culture, health care and support systems particular to Switzerland. This suggests, although further work is needed to confirm, that cultural/socio-geographic factors have a particular impact on caregivers' unmet needs. This is a novel finding.

Few previous studies have used the FACIT- Sp12, however, studies examining spiritual wellbeing of cancer caregivers do support the association reported in the current study between spiritual wellbeing, psychological morbidity and overall quality of life (Newberry et al., 2013, Cotton et al., 1999, Kim et al., 2011). Moreover, the finding that spousal caregivers had better spiritual wellbeing than adult children caregivers is supported by previous research; adult children caregivers have been found to have poorer spiritual adjustment compared with spouses/partners (Kim et al., 2007). Overall, caregivers' quality of life was lower than population norms (Bullinger and Kirchberger, 1998) but similar to other cancer caregiver groups (Kim et al., 2007).

It is well established that caregiving for a frail older adult with or without dementia leads to burden, including unmet needs (Riffin et al., 2019, Ringer et al., 2017) and that high levels of caregiver burden can consequently lead to suboptimal or unsafe care of the older adult receiving care (Lafferty et al., 2016). The findings of our study also reveal a considerable potential for high caregiver burden in the geriatric cancer care context and it would be prudent to aim at optimising the support for these caregivers, taking into account the individual needs in evolving care plans (Hamaker et al., 2018).

### Limitations and Strengths of the Study

The study was cross-sectional in nature and employed a consecutive sampling strategy. As only longitudinal studies are able to support conclusions regarding the direction of relationships, no causal inference can be drawn from the results. With the study's overall focus on caregivers of older people with cancer in the particular situation of receiving ambulatory chemotherapy, findings might not be transferable to caregivers looking after an older person with cancer at a different point in their treatment trajectory or other treatment modalities.

Research with caregivers in geriatric oncology settings is limited; a key strength of the study is the explicit recruitment of caregivers of people with cancer over 70 years of age having ambulatory chemotherapy. Further strengths relate to the evidence-based conceptual model underpinning the study and the use of a mixed-methods approach. The integration of data from the Phase 1 survey with the findings of the Phase 2 qualitative phase led to refined knowledge around caregiving tasks and caregiver roles, and identification of factors associated with psychological morbidity and quality of life in caregivers of older people with cancers, and potential reasons for these relationships.

### *CONCLUSIONS*

The findings of this study can be used to inform development of supportive interventions for caregivers of the geriatric oncology population, for example, interventions that enhance their spiritual wellbeing by enhancing their ability to find meaning in their caregiving experience may improve their health related quality of life and reduce psychological morbidity, particularly for younger (adult child) caregivers. If we recognize caregivers as worthy recipients of care then their right to assessment of their wellbeing and unmet needs must be acknowledged. Given that caregivers' experiences are associated with potentially detrimental consequences related to their wellbeing and quality of life, interventions to support informal caregivers in this context have to address the individual needs of caregivers and take account of possible differences that older age of the patients makes to caregivers' situations. Implications for practice include the need for regular assessments of caregivers' wellbeing

and clear and timely identification of their support needs. Taking these assessments as the bases for planning and delivering supportive interventions for caregivers may, in turn, enable caregivers to enhance the safety and wellbeing of the older people with cancer they look after.

- Before commencement of the study Ethics approval was granted by the provincial health research committees of the study sites [EKSG10/059, 24.03.2011].

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#### Conflict of interest statement

The authors have no other financial relationship with the trusts that supported the research in parts. We have full control of all primary data and agree to allow the journal to review the data if requested.

The authors have no conflict of interest to declare.

## REFERENCES

- ARCHBOLD, P. G., STEWART, B. J., GREENLICK, M. R. & HARVATH, T. 1990. Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*, 13, 375-84.
- ARMOOGUM, J., RICHARDSON, A. & ARMES, J. 2013. A survey of the supportive care needs of informal caregivers of adult bone marrow transplant patients. *Supportive Care in Cancer*, 21, 977-986.
- BULLINGER, M. & KIRCHBERGER, I. 1998. *SF36 health status questionnaire: Handbook [SF36 Fragebogen zum Gesundheitszustand: Handanweisung]*, Göttingen, Hogrefe.
- COLGROVE, L. A., KIM, Y. & THOMPSON, N. 2007. The effect of spirituality and gender on the quality of life of spousal caregivers of cancer survivors. *Annals of Behavioral Medicine*, 33, 90-98.
- COTTON, S., LEVINE, E., FITZPATRICK, C., DOLD, K. & TARG, E. 1999. Exploring the relationship among spiritual well-being, quality of life, and psychological adjustment in women with breast cancer. *Psycho-Oncology*, 8, 429 - 438.
- CRESWELL, J. & PLANO CLARK, V. 2011. *Designing and conducting mixed method research*, Thousand Oaks, Sage.
- DEEKEN, J. F., TAYLOR, K. L., MANGAN, P., YABROFF, K. R. & INGHAM, J. M. 2003. Care for the caregivers: a review of self-report instruments developed to measure the burden, needs, and quality of life of informal caregivers. *Journal of Pain & Symptom Management*, 26, 922-53.
- ESBENSEN, B. A. & THOMÉ, B. 2010. Being next of kin to an elderly person with cancer. *Scandinavian Journal of Caring Sciences*, 24, 648 - 654.
- FLETCHER, B. S., MIASKOWSKI, C., GIVEN, B. & SCHUMACHER, K. 2012. The cancer family caregiving experience: An updated and expanded conceptual model. *European Journal of Oncology Nursing*, 16, 387-98.
- GIRGIS, A., LAMBERT, S. & LECATHELINAIS, C. 2010. The supportive care needs survey for partners and caregivers of cancer survivors: development and psychometric evaluation. *Psycho-Oncology*, 20, 387-393.
- GIRGIS, A., LAMBERT, S. D., MCELDUFF, P., BONEVSKI, B., LECATHELINAIS, C., BOYES, A. & STACEY, F. 2013. Some things change, some things stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs. *Psychooncology*, 22, 1557-64.
- GIVEN, C., GIVEN, B., STOMMEL, M., COLLINS, C., KING, S. & FRANKLIN, S. 1992. The Caregiver Reaction Assessment (CRA) for caregivers to persons with chronic physical and mental impairments. *Research in Nursing & Health*, 15, 271 - 283.
- GLAJCHEN, M. 2012. Physical well-being of oncology caregivers: An important quality-of-life domain. *Seminars in Oncology Nursing*, 28, 226 - 235.
- GOLDBERG, D., GATER, R., SARTORIUS, N., USTUN, T., PICCINELLI, M., GUREJE, O. & RUTTER, C. 1997. The validity of two versions of the GHQ in the WHO study of mental illness in the general health care. *Psychological Medicine*, 27, 191 - 197.
- HAGEDOORN, M., SANDERMAN, R., BOLKS, H. N., TUINSTRRA, J. & COYNE, J. C. 2008. Distress in couples coping with cancer: A meta-analysis and critical review of role and gender effects. *Psychological Bulletin*, 134, 1 - 30.
- HAMAKER, M. E., PRINS, M. & VAN HUIS, L. H. 2018. Update in geriatrics: What geriatric oncology can learn from general geriatric research. *Journal of Geriatric Oncology*, 9, 393-397.
- HECKEL, L., FENNELL, K. M., REYNOLDS, J., OSBORNE, R. H., CHIRGWIN, J., BOTTI, M., ASHLEY, D. M. & LIVINGSTON, P. M. 2016. Unmet needs and depression among carers of people newly diagnosed with cancer. *European Journal of Cancer*, 51, 2049-2057.
- HOPKINS, S. A., BENTLEY, A., PHILLIPS, V. & BARCLAY, S. 2020. Advance care plans and hospitalized frail older adults: a systematic review. *BMJ Supportive & Palliative Care*, 10, 164.
- JANDA, M., STEGINGA, S., DUNN, J., LANGBECKER, D., WALKER, D. & EAKIN, E. 2008. Unmet supportive care needs and interest in services among patients with a brain tumour and their carers. *Patient Education & Counseling*, 71, 251-258.
- KIM, Y., BAKER, F. & SPILLERS, R. L. 2007. Cancer caregivers' quality of life: effects of gender, relationship, and appraisal. *Journal of Pain & Symptom Management*, 34, 294-304.

- KIM, Y., CARVER, C. S. & CANNADY, R. S. 2015. Caregiving motivation predicts long-term spirituality and quality of life of the caregivers. *Annals of Behavioral Medicine*, 49, 500-509.
- KIM, Y., CARVER, C. S., SPILLERS, R. L., CRAMMER, C. & ZHOU, E. S. 2011. Individual and dyadic relations between spiritual well-being and quality of life among cancer survivors and their spousal caregivers. *Psychooncology*, 20, 762-70.
- KITRUNGROTE, L. & COHEN, M. 2006. Quality of life of family caregivers of patients with cancer: A literature review. *Oncology Nursing Forum*, 33, 625 -632.
- LAFFERTY, A., FEALY, G., DOWNES, C. & DRENNAN, J. 2016. The prevalence of potentially abusive behaviours in family caregiving: Findings from a national survey of family carers of older people. *Age Ageing*, 45, 703-7.
- LI, Q. P., MAK, Y. W. & LOKE, A. Y. 2013. Spouses' experience of caregiving for cancer patients: a literature review. *International Nursing Review*, 60, 178-187.
- MCILFATRICK, S., SULLIVAN, K. & MCKENNA, H. 2006. What about the carers?: Exploring the experience of caregivers in a chemotherapy day hospital setting. *European Journal of Oncology Nursing*, 10, 294-303.
- MOFFATT, S., WHITE, M., MACKINTOSH, J. & HOWEL, D. 2006. Using quantitative and qualitative data in health services research – what happens when mixed method findings conflict? *BMC Health Services Research*, 6, 1-10.
- NEWBERRY, A. G., JEAN CHOI, C.-W., DONOVAN, H. S., SCHULZ, R., BENDER, C., GIVEN, B. & SHERWOOD, P. 2013. Exploring spirituality in family caregivers of patients with primary malignant brain tumors across the disease trajectory. *Oncology Nursing Forum*, 40, E119 - 125.
- NORTHOUSE, L. L., KATAPODI, M. C., SCHAFENACKER, A. M. & WEISS, D. 2012. The Impact of Caregiving on the Psychological Well-Being of Family Caregivers and Cancer Patients. *Seminars in Oncology Nursing*, 28, 236-245.
- O'CATHAIN, A., E., M. & NICHOLL, J. 2010. Three techniques for integrating data in mixed methods studies. *British Medical Journal*, 341, 1147-1150.
- PEARLIN, L. I., MULLAN, J. T., SEMPLE, S. J. & SKAFF, M. M. 1990. Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- PETERMAN, A., FITCHETT, G., BRADY, M., HERNANDEZ, L. & CELLA, D. 2002. Measuring spiritual wellbeing in people with cancer: The functional assessment of chronic illness therapy - spiritual well-being scale (FACIT-Sp). *Annals of Behavioral Medicine*, 24, 49 - 58.
- PINQUART, M. & SÖRENSEN, S. 2011. Spouses, adult children, and children-in-law as caregivers of older adults: A meta-analytic comparison. *Psychology and Aging*, 26, 1-14.
- POLIT, D. 2010. *Statistics and data analysis for nursing research*, Boston, Pearson.
- REAM, E., PEDERSEN, V.H., OAKLEY, C, RICHARDSON, A, TAYLOR, C, VERITY, R. 2013. Informal carers' experiences and needs when supporting patients through chemotherapy: a mixed method study. *European Journal of Cancer Care*, 22, 797 - 806.
- RIFFIN, C., VAN NESS, P. H., WOLFF, J. L. & FRIED, T. 2019. Multifactorial examination of caregiver burden in a national sample of family and unpaid caregivers. *Journal of American Geriatric Society*, 67, 277-283.
- RINGER, T., HAZZAN, A. A., AGARWAL, A., MUTSAERS, A. & PAPAIOANNOU, A. 2017. Relationship between family caregiver burden and physical frailty in older adults without dementia: a systematic review. *Systematic Reviews*, 6, 55.
- RITCHIE, J., SPENCER, L. & O'CONNOR, W. 2009. Carrying out qualitative analysis. In: RICHIE, J. & LEWIS, J. (eds.) *Qualitative research practice: A guide for social science students and researchers*. London: Sage.
- SANSON-FISHER, R., GIRGIS, A., BOYES, A., BONEVSKI, B., BURTON, L. & COOK, P. 2000. The unmet supportive care needs of patients with cancer. *Cancer*, 88, 226-237.
- SKLENAROVA, H., HAUN, M. W., KRÜPELMANN, A., FRIEDERICH, H. C., HUBER, J., THOMAS, M., WINKLER, E. C., GIRGIS, A., DINKEL, A., HERZOG, W. & HARTMANN, M. 2015a. Psychometric evaluation of the German Version of the Supportive Care Needs Survey for Partners and Caregivers (SCNS-P&C-G) of cancer patients. *European Journal of Cancer Care*, 24, 884-897.



- SKLENAROVA, H., KRÜMPELMANN, A., HAUN, M. W., FRIEDERICH, H.-C., HUBER, J., THOMAS, M., WINKLER, E. C., HERZOG, W. & HARTMANN, M. 2015b. When do we need to care about the caregiver? Supportive care needs, anxiety, and depression among informal caregivers of patients with cancer and cancer survivors. *Cancer*, 121, 1513-1519.
- STENBERG, U., RULAND, C. M. & MIASKOWSKI, C. 2010. Review of the literature on the effects of caring for a patient with cancer. *Psycho-Oncology*, 19, 1013-1025.
- TABACHNICK, B. & FIDELL, L. 2001. *Using multivariate statistics*, New York, Harper Collins.
- TAN, J. Y. S., LIM, H. A., KUEK, N. M. Y., KUA, E. H. & MAHENDRAN, R. 2015. Caring for the caregiver while caring for the patient: exploring the dyadic relationship between patient spirituality and caregiver quality of life. *Supportive Care in Cancer*, 23, 3403-3406.
- TURNER, D., ADAMS, E., BOULTON, M., HARRISON, S., KHAN, N., ROSE, P., WARD, A. & WATSON, E. 2013. Partners and close family members of long-term cancer survivors: Health status, psycho-social well-being and unmet supportive care needs. *Psycho-Oncology*, 22, 22 - 19.
- VAN CLEAVE, J. H., KENIS, C., SATTAR, S., JABLOO, V. G., AYALA, A. P. & PUTS, M. 2016. A research agenda for gero-oncology nursing. *Seminars in Oncology Nursing*, 32, 55-64.
- WARE, J., KOSINSKI, M. & KELLER, S. 1996. A 12-item Short-Form Health Survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, 34, 220-233.
- WILDIERS, H., HEEREN, P., PUTS, M., TOPINKOVA, E., JANSSEN-HEIJNEN, M. L. G., EXTERMANN, M., FALANDRY, C., ARTZ, A., BRAIN, E., COLLOCA, G., FLAMAING, J., KARNAKIS, T., KENIS, C., AUDISIO, R. A., MOHILE, S., REPETTO, L., VAN LEEUWEN, B., MILISEN, K. & HURRIA, A. 2014. International Society of Geriatric Oncology consensus on geriatric assessment in older patients with cancer. *Journal of Clinical Oncology*, 32, 2595-2603.