

Informal caregivers of advanced-stage cancer patients: Every second is at risk for psychiatric morbidity

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Abstract

Purpose Informal caregivers of advanced cancer patients are known to suffer from high distress due to their caregiving responsibilities. Nevertheless, a comprehensive evaluation of psychiatric morbidity is often missing in clinical practice due to time resources, and mental health problems may be unnoticed in this population. A feasible approach is needed to identify caregivers at risk for psychiatric disorders to offer targeted interventions and enhance their well-being.

Methods This cross-sectional, multi-institutional study screened 345 caregivers of advanced cancer patients for psychiatric disorders (i.e., depression, anxiety, posttraumatic stress disorder, and alcohol abuse/dependence) and assessed factors potentially associated with mental health diagnoses (including socio-demographic factors, burden, hope, caring-related quality of life, and coping preferences).

Results Overall, almost 52 % of participants had one or more suspected psychiatric disorders, with anxiety being the most prevalent. Perceived hope, higher burden, and more emotion-oriented coping were associated with psychiatric morbidity in

this sample. Spouses and parents showed significantly more symptoms of psychiatric disorders than other relatives.

Conclusions This study confirms the high risk of informal caregivers of advanced cancer patients to develop psychiatric disorders and suggests a practically feasible approach to identify at risk caregivers to offer support.

Keywords Caregiver · Psychiatric morbidity · Burden · Cancer · Palliative care · Mental health

Introduction

Despite major advances in the treatment of cancer during the past few decades, definite cure from most oncological diseases is still often out of reach. Advanced cancer care is currently undergoing a fundamental process of transformation, shifting the focus from an acute illness with short-term outcome towards more stable and chronic conditions. This process foresees an improved survival leading to a rising number of patients with permanent disabilities and an increasing need for long-term support. Since advanced therapy cannot be administered solely by hospitals, many advanced cancer patients receive continuous treatment in outpatient settings in the course of their treatment, where informal caregivers play a critical role [1, 2].

By providing physical care as well as emotional, social, and financial support, caregivers have to fulfill a demanding and challenging role [3], which puts them at increased risk of developing mental health problems. The impact of these responsibilities on caregivers' emotional and physical well-being is documented by multiple studies [4–8]. Hence, in light of the added care load associated with the ever-increasing number of chronic cancer patients, it is necessary to reassess the psychiatric affection of such caregivers since it

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may seriously impact their ability to fulfill their caring duties. In particular, informal caregivers show higher levels of stress and depression and lower levels of subjective well-being and physical health as compared to age-matched non-caregivers [4]. Additionally, the prevalence of anxiety appears elevated in caregivers compared with the general US norm population (45 % in male caregivers and 13 % in the age-adjusted norm and 47 vs. 18 % in females) [5].

However, research on caregivers is methodologically complex and challenging. Psychiatric disorders in caregivers of advanced cancer patients, other than depression or anxiety, have so far received little attention in this research field. Current studies assess these disorders separately from each other, rather than focusing on a comprehensive evaluation of the combined prevalence of psychiatric morbidities in the caregiver population. This knowledge about caregivers' mental health status as well as about the psychological, social, and physical correlates of caregiver distress is an important prerequisite for the development of successful preventive and supportive intervention strategies. Considering time resources, screening for psychiatric disorders in caregivers may not be possible on a routine clinical basis, and currently, there are no recommendations to support clinicians in their decision as to which extent caregivers should be offered mental health support and treatment. Determining simple predictors for psychiatric morbidity could be a superior attempt to identify and address caregivers at risk.

Variables that have been associated with caregivers' mental health include the perception of burden [6]; higher unmet needs, especially the lack of emotional and informational support [9]; and patients' declining functioning [7, 8]. These known factors are not exhaustive, they may be difficult to assess in daily clinical routine, and the direction of causality is not always clear. Socio-demographic factors such as gender [8, 10, 11] and the weekly time spent for informal caregiving [12] have been proposed as predictors for caregivers' mental health. A focus on such easily recognizable variables might be a feasible approach to support clinicians' decision-making in practice. Nevertheless, it is important to consider correlates of psychiatric morbidity as bidirectional, serving not only as predictors for the development of disorders but also as possibly impaired by them. This knowledge can be used to include these factors as target variables for interventions.

The main outcome of this multi-institutional, prospective study was the extent of psychiatric morbidity in informal caregivers of advanced cancer patients at baseline. In addition, we also assessed factors that are possibly associated with suspected mental health diagnoses (including socio-demographic factors, burden, hope, caring-related quality of life, and coping mechanisms) in order to define feasible factors that might support clinicians in detecting caregivers at risk

for psychiatric morbidity. Our results aim to improve current strategies for enhancing well-being, health, and daily functioning in informal caregivers.

Methods

Setting and participants

This analysis was part of a multi-institutional, prospective study, screening informal caregivers of advanced cancer patients for a wide range of psychiatric diagnoses and assessing potentially associated factors for psychiatric morbidity. All participants were self-identified primary caregivers of an advanced cancer patient. Inclusion criteria for caregivers were age over 18 years, fluency in the German language, and capability to give written informed consent. Recruitment was conducted at different oncological inpatient clinics at the Medical University of Vienna and two major city hospitals. Study staff screened patients' records biweekly for patients who fulfilled the inclusion criteria (i.e., advanced cancer diagnosis, with an estimated life expectancy less than 6 months rated by a physician) and approached the caregivers by sending an initial information letter, followed by a telephone call to further inform them about the study. After giving informed consent, participants received the baseline questionnaires and consent form by mail, together with a pre-paid return envelope. The sample size was chosen to detect a small effect size at alpha 0.05 with a power of 0.90. The study protocol was approved by the Ethics Committee of the Medical University of Vienna (1003/2010).

Measurement tools

All questionnaires in the present study are validated and internationally established and therefore ensure high reliability and validity. On all scales, higher scores represent higher presence of the respective underlying construct.

Socio-demographic variables and caring information

Assessed socio-demographic and caring information included age, gender, relationship with the patient, and length of overall caring period.

Psychiatric morbidity

The Impact of Event Scale—Revised consists of 22 items, reflecting the DSM-IV criteria for posttraumatic stress disorder (PTSD) in three subscales (i.e., intrusion, avoidance, and hyperarousal) [13, 14]. Each item is rated for the frequency of occurrence of the respective symptom (0 = not at all, 1 = rarely, 3 = sometimes, 5 = often). A total score of the subscales can be

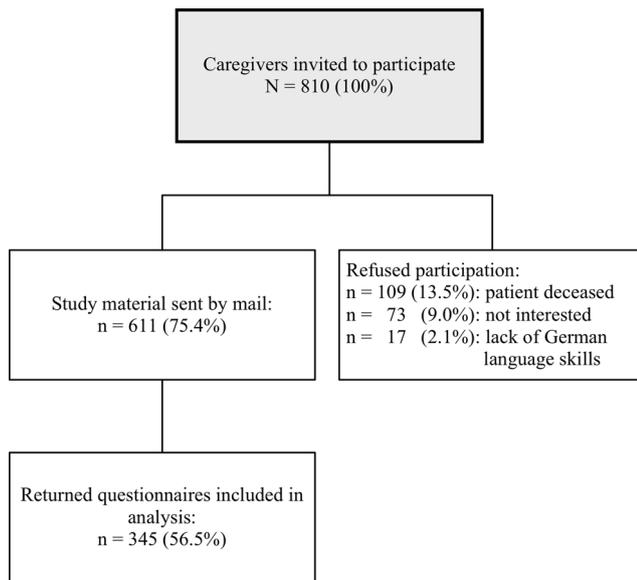


Fig. 1 Participant inclusion data

calculated for continuous analysis, and a cutoff score differentiating between a likely PTSD or no PTSD is available after transformation of the scores (values ≥ 0.0 are then considered as likely PTSD) [14].

The CAGE questionnaire [15] is a screening tool for alcoholism, consisting of four questions rated with 0 (no) or 1 (yes). The total score ranges from 0 to 4; values greater than or equal to 2 indicate a possible alcohol abuse or dependence.

The Hospital Anxiety and Depression Scale (HADS-D) in the German translation [16] assesses levels of depression and anxiety in patients with a somatic disease. The questionnaire has also been validated in German for the general population [17]. It consists of 14 items, each rated on a 4-point Likert scale (ranging from 0 = not present to 3 = considerable). A sum score is calculated for each subscale (i.e., depression and anxiety). Cutoff values, discriminating between normal (score less than 8), borderline (8–10), and abnormal (greater than 10) scores, for both subscales were published [18].

Variables assumed to impact on psychiatric morbidity

The assessed variables in this study are hypothesized to be associated with psychiatric morbidity. All of them can be considered either as predictor for the development or as subsequently altered by the presence of psychiatric disorders.

The Zarit Caregiver Burden Interview (ZBI) was used to assess the burden in caregivers of cancer patients. For the palliative setting, the 12-item short version (ZBI-12) seemed most appropriate [19]. Every item is rated on a 5-point Likert scale (ranging from 0 = never to 4 = always). The overall burden is assessed by a total score of all items.

The Quality of Life in Life-Threatening Illness—Family Carer Version (QOLLTI-F) questionnaire was used in a

translated version [20], deriving from the original version from Cohen et al. [21]. The questionnaire comprises 16 items rated on an 11-point Likert scale (ranging from 0, indicating the worst situation, and 10, indicating the best situation). The scale results in a mean total score and potentially seven subscales and three additional descriptive single items. It assesses relevant aspects of quality of life, including environment, patient state, carer's own state, carer's outlook, quality of care, relationships, and financial worries.

The Integrative Hope Scale (IHS) consists of 23 items, comprising four subscales (i.e., trust and confidence, lack of perspective, positive future orientation, social relations, and personal value) [22]. Every item is rated on a 6-point Likert scale (ranging from 1 = strongly disagree to 6 = strongly agree).

The Coping Inventory for Stressful Situations (CISS) contains 24 items, rated on a 5-point Likert scale (from 1 = very unlikely to 5 = very likely) [23]. Each item asks participants to indicate their engagement in various coping mechanisms during stressful situations, resulting in three preferences for certain coping strategies (i.e., task-oriented coping, emotion-oriented coping, and avoidance-oriented coping). Whereas task-oriented coping focuses on direct actions to alter stressful situations, emotion-oriented coping aims to modify one's own emotional response on these situations. Avoidance-oriented coping consists of distraction and social diversion in order to manage stress.

Data analysis

Descriptive data are presented in absolute numbers and percentages. Depending on data distribution, means (with standard deviation) or medians (with interquartile ranges) are reported. Categorical data were tested using Pearson's chi-square tests; in cases of an expected frequency < 5 , Fisher's exact tests were used. Differences between groups were analyzed using Student's *t* test, one-way analyses of variance (ANOVA), or the parameter-free Mann-Whitney *U* and Kruskal-Wallis tests. Post hoc analyses were conducted for significant differences in variables comprising more than two groups using Mann-Whitney *U* tests. Hypotheses were tested two-sided with a significance level of 5 %. Because of the exploratory nature of the present study, no correction for multiple testing was applied. For estimation of effect sizes in significant results, Pearson's correlation coefficient (*r*) or phi coefficient (φ), as a quantitative measure of the strength of a result, is reported with the following common interpretation: 0.1 = small, 0.3 = moderate, and 0.5 = large effect size [24]. Analysis was performed using SPSS 17.0 for Windows (SPSS Inc., Chicago, IL, USA).

Table 1 Caregivers' socio-demographic characteristics and caring arrangements ($N = 345$)

Variable		Mean (SD, range) N (%)
Age ($n = 335$)		53.39 years (± 14.51 , 18–86)
Gender ($n = 345$)	Female	209 (60.6 %)
Relationship to patient ($n = 345$)	Spouse/partner	174 (50.4 %)
	Child	103 (29.9 %)
	Sibling	9 (2.6 %)
	Parent	18 (5.2 %)
	Friend	11 (3.2 %)
	Other	30 (8.7 %)
	Living situation ($n = 344$)	Same household
	Different household	148 (43 %)
Educational level ($n = 344$)	Primary education (up to age 14)	27 (7.8 %)
	Secondary education (age 15–18)	140 (40.7 %)
	Vocational training	104 (30.2 %)
	Higher education (above 18)	72 (20.9 %)
	No educational qualification	1 (0.3 %)
Length of overall caring time ($n = 339$)	<6 months	105 (31 %)
	6–12 months	66 (19.5 %)
	1–2 years	60 (17.7 %)
	2–3 years	34 (10 %)
	>3 years	74 (21.8 %)
Weekly number of hours spent with caring tasks ($n = 337$)	<10	75 (22.3 %)
	10–20	88 (26.1 %)
	20–40	84 (25 %)
	>40	90 (26.7 %)

Results

Demographic characteristics of the cohort

Overall, 345 of 611 contacted caregivers gave their written informed consent and participated in the present study. Participant inclusion data are shown in Fig. 1. Their socio-demographic characteristics and caring arrangements are displayed in Table 1. We assessed the prevalence of psychiatric disorders followed by two separate group comparisons: first, we compared two groups, i.e., those with any disorder vs. those with none; second, we compared four graded groups, i.e., those with no, one, two, or three/four likely psychiatric disorders for better differentiation of results.

Psychiatric morbidity in caregivers

Overall, 51.6 % of participants had one or more suspected psychiatric disorders (i.e., PTSD, alcohol disorder, depression, and/or anxiety). The distribution of suspected psychiatric disorders in this sample is displayed in Table 2.

Comparing the two groups of those with and without possible psychiatric disorders, significant differences were found for relationship with the patient, caring-related quality of life, hope, burden, and two of the three coping mechanisms (i.e., task- and emotion-oriented coping). A significant difference

Table 2 Prevalence of suspected psychiatric disorders in caregivers of advanced cancer patients

Questionnaires	Screening results for disorders	n (%)
IES-R ($n = 332$)	Possible PTSD	62 (18.7 %)
	No PTSD	270 (81.3 %)
CAGE ($n = 318$)	Possible alcohol abuse/dependence	36 (11.3 %)
	No alcohol abuse/dependence	282 (88.7 %)
HADS ($n = 340$)	Possible anxiety disorder	116 (34.1 %)
	Borderline score	89 (26.2 %)
	No anxiety disorder	135 (39.7 %)
	Possible depression	72 (21.3 %)
	Borderline score	72 (21.3 %)
	No depression	194 (57.4 %)

Table 3 Impact of caregivers' socio-demographics, caring arrangements, and other associated variables on psychiatric morbidity

	Group 0: no psychiatric disorders (<i>n</i> = 158-167)	Group 1: 1 suspected psychiatric disorder (<i>n</i> = 86-93)	Group 2: 2 suspected psychiatric disorders (<i>n</i> = 61-64)	Group 3: 3 or 4 suspected psychiatric disorders (<i>n</i> = 19-21)	Significant differences between groups (<i>P</i> < 0.05)
Age	53.27 (14.17)	53.85 (15.50)	53.77 (15.02)	51.10 (11.42)	n.s.
Gender					n.s.
Female	97 (58.1 %)	57 (61.3 %)	41 (64.1 %)	14 (66.7 %)	
Male	70 (41.9 %)	36 (38.7 %)	23 (35.9 %)	7 (33.3 %)	
Caring-related quality of life (QOLLI-F)	6.65 (1.63)	6.42 (1.38)	6.17 (1.50)	6.06 (1.49)	n.s.
Perceived hope (IHS)	108.32 (13.93)	102.30 (15.78)	104.55 (14.57)	102.09 (14.35)	0 > 1
Burden (ZBI)	13.79 (8.12)	16.23 (10.04)	16.41 (8.55)	18.86 (9.48)	0 < 2, 3
Task-oriented coping (CISS)	3.58 (0.70)	3.49 (0.67)	3.61 (0.71)	3.60 (0.71)	n.s.
Emotion-oriented coping (CISS)	2.41 (0.71)	2.65 (0.73)	2.71 (0.64)	2.98 (0.91)	0 < 1 < 2 < 3
Avoidance-oriented (CISS)	2.82 (0.75)	2.84 (0.90)	2.92 (0.88)	2.95 (0.74)	n.s.

in the presence of suspected psychiatric disorders was evident for the overall comparison of caregivers' relationship to the patient ($P = 0.014$; $\varphi = 0.203$). Regarding caregiver's relationship, the highest average number of likely psychiatric disorders was found in parents (1.33 suspected psychiatric disorders in average), children (0.91), siblings (0.78), and spouses (0.77), and the lowest psychiatric morbidity was evident in friends (0.55). Those with suspected disorders had a significantly lower caring-related quality of life ($P = 0.036$; $r = 0.117$), lower perceived hope ($P = 0.001$; $r = 0.177$), and a higher burden ($P = 0.003$; $r = 0.158$). They used emotion-oriented coping significantly more often ($P < 0.001$; $r = 0.205$) and applied task-oriented coping less often ($P = 0.027$; $r = 0.020$) than those without. Age, length of caring time, gender, and avoidance-oriented coping had no significant relationship with psychiatric morbidity.

For further analyses, participants with possible psychiatric disorders were split into groups according to their number of suspected psychiatric disorders. While 48.4 % of caregivers had no suspected psychiatric disorders, 27 % of caregivers ($n = 93$) had one, 18.6 % ($n = 64$) had two, 5.5 % ($n = 19$) had three, and 0.6 % ($n = 2$) had four likely psychiatric disorders. Participants with three and four suspected disorders were merged into one group due to the small sample size.

Detailed comparison of groups

Results for the distribution of the assessed variables across the four groups (i.e., no, one, two, or three/four suspected psychiatric disorders) are shown in Table 3.

A significant relationship was found for perceived hope ($P = 0.014$). Post hoc comparisons showed significantly higher levels of hope specifically in caregivers with no psychiatric morbidity compared to those with one suspected disorder (Table 3). Likewise, a significant relationship between burden and psychiatric morbidity was evident ($P = 0.027$). The burden increased with the number of suspected psychiatric disorders (i.e., two or three disorders) compared to those with no suspected disorder (Table 3).

While emotion-oriented coping was also significantly associated with the number of suspected psychiatric disorders ($P = 0.001$), avoidance coping and task-oriented coping were not. The use of emotion-oriented coping showed a steady progression with the number of suspected psychiatric disorders, as post hoc tests for differences between all groups were significant (Table 3).

No significant differences between groups were found for age, gender, caregivers' relationship to the patient, the length of caring time, as well as caring-related quality of life.

Discussion

A growing body of literature shows that informal caregivers are at high risk of suffering from concurrent emotional distress due to the extensive demands associated with providing care to a person with advanced cancer. Throughout the illness trajectory, normal feelings of vulnerability, sadness, and fear can develop into disabling mental health problems and may further cause deterioration in physical health [25]. Given the high prevalence of cancer, a paradigm shift in advanced cancer

care, and the rising number of patients, caregivers are a critical element of home care. However, if distress becomes overwhelming, home care support may not only be seriously jeopardized but might also lead to negative consequences for the caregivers and the patients' clinical condition and can also have an impact on the health care system. Hence, it is undoubtedly justified for professional health care providers to be sensitive to caregivers' distress and to provide supportive and preventive interventions.

To our knowledge, this is the first study that examines the prevalence of psychiatric comorbidities in informal caregivers, including the screening for four different psychiatric disorders (i.e., PTSD, alcohol disorder, depression, and/or anxiety). Overall, 51.6 % of participants in the current study had one or more suspected psychiatric disorders, with anxiety being the most prevalent (34.1 %) and alcohol abuse/dependence the least prevalent (11.3 %). A possible PTSD was present in 18.7 % of participants and depression was suspected in 21.3 %.

Our results confirm previous findings, also showing anxiety disorders to be the most common and substance use disorders the least prevalent disorders in informal caregivers of a mixed patient group [26]. If using the same cutoff value as that of Grov et al. [5] (i.e., greater than/equal to 8), the authors suggest a lower prevalence for depression (24 % in their study, compared to 43 % in our study) and also a lower prevalence for anxiety (46 vs. 60 %, respectively) in a cross-sectional assessment of a smaller cohort compared to our results. Cochrane et al. [26] also report a significantly lower prevalence of depression and anxiety, assessed in a large, representative epidemiological survey. A recent study from Williams et al. [27] showed the same prevalence for depression as that in our study (21 %), and the study sample of Braun et al. [28] consisted of 39 % of participants with elevated depression levels. These inconsistencies may be caused by varying assessment modalities (i.e., external assessment via diagnostic interview) and instruments (e.g., HADS vs. Beck's Depression Inventory). Nevertheless, all mentioned studies show a higher prevalence of depression and anxiety compared to non-caregivers. This seems most important as it shows the high risk of informal caregivers to suffer from mental health problems.

Due to the increased prevalence of psychiatric disorders in the overall caregiver population, the application of targeted intervention strategies for informal caregivers is crucial. While in some caregivers, mental health problems may be temporary, subsiding after the patient's death, others may experience clinically relevant disorders and require professional treatment to ensure well-being and prevent long-term disability [29]. Specific interventions for caregivers have already been suggested for this purpose, focusing mainly on psychoeducation, skills training, and therapeutic counseling [30–32].

Evidence on the direct impact on psychiatric morbidity is weak, as many interventions only focus on outcomes in self-efficacy, burden, and quality of life [30]. However, as an association of these factors with psychiatric disorders seems likely [6], interventions mentioned above might be appropriate in reducing psychiatric morbidity in informal caregivers. Additionally, focusing on the improvement of some of these variables in interventions (i.e., quality of life, coping mechanisms, hope, and burden) might have a positive impact on the psychiatric morbidity in caregivers.

Literature suggests that, despite their needs and the availability of interventions, caregivers often underuse mental health services due to their time-consuming nature, commitment to the caregiving role (i.e., prioritizing the patients' needs), financial factors, or a negative attitude towards mental health professionals [33]. As a consequence, receipt of mental health support for informal caregivers might sometimes be solely based on the evaluation of health care professionals or on caregivers' knowledge or their request of services. Since screening for psychiatric disorders of caregivers can hardly be implemented in daily clinical routine, a fast and comprehensive identification of predictors for psychiatric morbidity seems crucial to allow a feasible and straightforward approach to identifying caregivers at risk. For this purpose, we split all participants with suspected psychiatric disorders into groups according to their number of disorders. Although a causal interpretation of predictors cannot be made due to the cross-sectional study design, the analysis with smaller, more differentiated groups allows for estimation of the impact of different variables on psychiatric morbidity.

A factor related to caregivers' psychiatric morbidity is perceived hope, as it was significantly higher in caregivers without psychiatric diagnoses. Importantly, this factor has not yet been assessed in association with caregivers' mental health but is often used as an outcome or treatment variable of caregiver interventions [34–36] and might therefore serve as a valuable factor for therapeutic use. So far, perceived burden of informal caregivers is the only variable in this study, which has previously been used as a predictor for depression [6]. In our population, higher burden was also associated with higher overall psychiatric morbidity. Although reported in multiple previous studies [37, 38], caring-related quality of life is not critically impaired through caregiving in this cohort. This might be due to a particularly low quality of life in our study participants, regardless of suspected psychiatric disorders.

Coping mechanisms are regarded as bidirectional factors, influencing mental health on the one hand and on the other hand being influenced by mental health [39]. Considering this, it is not surprising that in the present study caregivers with more psychiatric diagnoses used other coping mechanisms than those with less diagnoses. In detail, emotion-oriented coping was more frequently used the more suspected disorders a caregiver had. This coping mechanism involves

strategies that aim to reduce negative emotional responses associated with a stressful situation (e.g., through distraction, cognitive reappraisal, or suppression).

In conclusion, two explanations seem possible for all assessed variables: first, the burden of a higher number of psychiatric diagnoses might impair these variables (i.e., hope, burden, and coping mechanisms) or second, reduced scores of these variables could promote the development of psychiatric disorders. Nevertheless, these factors may all serve as valuable target variables for therapeutic interventions with this client group.

Considering limited personal and time resources in daily clinical routine, socio-demographic factors might serve as a more feasible approach to identify caregivers at risk. In our study, being closer to the patient was significantly more often associated with one or more suspected psychiatric disorders. A possible association between the caregivers' relationship to the patient and their psychiatric disorders has to our knowledge not been assessed so far, but a closer relationship to the patient has previously been linked to more stress, increased workload, as well as other negative consequences on caregivers' well-being [40]. In our sample, siblings, parents, children, and spouses had the most suspected psychiatric disorders, whereas friends and other relationships (e.g., cousins, in-laws, and grandchildren) had a significantly lower psychiatric morbidity. This factor might be an indicator to identify caregivers at risk, but they certainly need further studies to assess the causality between socio-demographics and caregivers' mental health.

Limitations

Importantly, in the present study, a comparatively high cutoff value for anxiety and depression was used in order to differentiate between those participants with a borderline amount of symptoms and those with many symptoms of anxiety or depression. This approach is rather conservative, which might result in fewer but better confirmed diagnoses of depression or anxiety.

Considering our response rate of 42.6 % of those eligible and 56.5 % of those contacted, we might not have reached especially burdened caregivers, who did not participate due to the fact that the patient had died in the meanwhile or who did not feel able to participate in a study due to their high burden. Our results may therefore represent a conservative estimate of caregiver burden. Nevertheless, in regard to the particularly stressful situation of informal caregivers of advanced cancer patients, our response rate can be considered as quite good compared to other studies of informal caregivers (e.g., 41 % in Grov et al. [5] or 45 % in Fromme et al. [8]).

The relatively low prevalence of alcohol abuse/disorder in this sample could be explained by social desirability and a certain inhibition to admit alcohol-related issues, as a

relatively high proportion of participants did not answer all four questions in the CAGE screening questionnaire. Only 318 questionnaires were completed, which leads to the suspicion that the actual prevalence of alcohol disorders may be higher.

In addition, our study design does not allow interpretation of the direction of causality. Nevertheless, the analysis with graded groups allows the estimation of the impact of different variables on psychiatric morbidity.

Future research and implementation of results

As palliative care wards comprise of multidisciplinary teams (i.e., physicians, nurses, psychologists, spiritual care workers, dieticians, and volunteers), regular team meetings can be used to ascertain caregivers that seem at risk. Additionally, a short screening questionnaire for every caregiver in daily clinical routine should be developed and evaluated in future studies, considering all possible risk factors as mentioned in this report. The possible implementation of regular support interventions for caregivers should be evaluated, considering their limited time resources and particular support needs.

Conclusions

Informal caregivers of advanced cancer patients are at high risk of developing psychiatric disorders. In order to support their functioning and well-being in the face of ongoing caring duties for patients, the feasible identification of at risk caregivers is crucial. Identifying those at risk for developing mental health problems is the first step for the provision of targeted preventive and therapeutic interventions.

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Conflict of interest The authors declare that they have no competing interests.

References

1. Given BA, Given CW, Kozachik S (2001) Family support in advanced cancer. *A Cancer J Clin* 51:213–231
2. Tangka FK, Trogdon JG, Richardson LC, et al. (2010) Cancer treatment cost in the United States: has the burden shifted over time? *Cancer* 116:3477–3484
3. Deshields TL, Rihanek A, Potter P, Zhang Q, Kuhrik M, Kuhrik N, et al. (2012) Psychosocial aspects of caregiving: perceptions of

- cancer patients and family caregivers. *Support Care Cancer* 20(2): 349–356
4. Pinquart M, Sörensen S (2003) Differences between caregivers and noncaregivers in psychological health and physical health: a meta-analysis. *Psychol Aging* 18(2):250–267
 5. Grov EK, Dahl AA, Moum T, Fosså SD (2005) Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol* 16(7):1185–1191
 6. Young SR, Young HY, Park S, Dong OS, Kwang ML, Han JY, et al. (2008) Depression in family caregivers of cancer patients: the feeling of burden as a predictor of depression. *J Clin Oncol* 26(36): 5890–5895
 7. Dumont S, Turgeon J, Allard P, Gagnon P, Charbonneau C, Vézina L (2006) Caring for a loved one with advanced cancer: determinants of psychological distress in family caregivers. *J Palliat Med* 9(4):912–921
 8. Fromme EK, Drach LL, Tolle SW, Ebert P, Miller P, Perrin N, et al. (2005) Men as caregivers at the end of life. *J Palliat Med* 8(6):1167–1175
 9. Lambert SD, Girgis A, Lecathelinais C, Stacey F (2013) Walking a mile in their shoes: anxiety and depression among partners and caregivers of cancer survivors at 6 and 12 months post-diagnosis. *Support Care Cancer* 21(1):75–85
 10. Gilbar O (1999) Gender as a predictor of burden and psychological distress of elderly husbands and wives of cancer patients. *Psycho-Oncology* 8(4):287–294
 11. Perz J, Ussher JM, Butow P, Wain G (2011) Gender differences in cancer carer psychological distress: an analysis of moderators and mediators. *Eur J Cancer Care (Engl)* 20(5):610–619
 12. Cannuscio CC, Colditz GA, Rimm EB, Berkman LF, Jones CP, Kawachi I (2004) Employment status, social ties, and caregivers' mental health. *Soc Sci Med* 58(7):1247–1256
 13. Weiss D, Marmar C (1996) The Impact of Event Scale—Revised. In: Wilson J, Keane T (eds) *Assessing psychological trauma and PTSD*. Guilford, New York, pp. 399–411
 14. Maercker A, Schützwohl M (1998) Erfassung von psychischen Belastungsfolgen: Die Impact of Event Skala-revidierte Version. *Diagnostica* 44:130–141
 15. Ewing J (1968) Detecting alcoholism; the CAGE questionnaire. *J Am Med Assoc* 252:1905–1907
 16. Zigmond A (1995) Hospital anxiety and depression scale: deutsche Version HADS-D; ein Fragebogen zur Erfassung von Angst und Depressivität in der somatischen Medizin. Huber
 17. Hinz A, Brähler E (2011) Normative values for the Hospital Anxiety and Depression Scale (HADS) in the general German population. *J Psychosom Res*. Elsevier Inc. 71(2):74–78
 18. Zigmond AS, Snaith RP (1983) The Hospital Anxiety and Depression Scale. *Acta Psychiatr Scand* 67:361–370
 19. Higginson IJ, Gao W, Jackson D, Murray J, Harding R (2010) Short-form Zarit Caregiver Burden Interviews were valid in advanced conditions. *J Clin Epidemiol* 63:535e542
 20. Schur S, Ebert-Vogel A, Amering M, Masel EK, Neubauer M, Schrott A, et al. (2014) Validation of the “Quality of Life in Life-Threatening Illness—Family Carer Version” (QOLLTI-F) in German-speaking carers of advanced cancer patients. *Support Care Cancer* 22:2783–2791
 21. Cohen R, Leis AM, Kuhl D, Charbonneau C, Ritvo P, Ashbury FD (2006) QOLLTI-F: measuring family carer quality of life. *Palliat Med* 20:755–757
 22. Schrank B, Woppmann A, Sibitz I, Lauber C (2011) Development and validation of an integrative scale to assess hope. *Health Expect* 14(4):417–428
 23. Endler N, Parker J (1990) *Coping inventory for stressful situations*. Multi-Health Systems Inc., Toronto
 24. Field A (2009) *Discovering statistics using SPSS*. Sage Publications, London
 25. Carlson LE, Bultz BD, Specia M, Pierre MS (2000) Partners of cancer patients: part I. Impact, adjustment, and coping across the illness trajectory. *J Psychosoc Oncol* 18(2):37–41
 26. Cochrane JJ, Goering PN, Rogers JM (1997) The mental health of informal caregivers in Ontario: an epidemiological survey. *Am J Public Health* 87(12):2002–2007
 27. Williams A-L, Holmes Tisch AJ, Dixon J, et al. (2013) Factors associated with depressive symptoms in cancer family caregivers of patients receiving chemotherapy. *Support Care Cancer* 21:2387–2394
 28. Braun M, Mikulincer M, Rydall A, et al. (2007) Hidden morbidity in cancer: spouse caregivers. *J Clin Oncol* 25:4829–4834
 29. Aneshensel CS, Botticello AL, Yamamoto-Mitani N (2004) When caregiving ends: the course of depressive symptoms after bereavement. *J Health Soc Behav* 45(4):422–440
 30. Northouse LL, Katapodi MC, Song L, Zhang L, Mood DW (2010) Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *A Cancer J Clin* 60(5):317–339
 31. Kurtz ME, Kurtz JC, Given CW, Given B (2005) A randomized, controlled trial of a patient/caregiver symptom control intervention: effects on depressive symptomatology of caregivers of cancer patients. *J Pain Symptom Manag* 30(2):112–122
 32. Toseland RW, Blanchard CG, McCallion P (1995) A problem solving intervention for caregivers of cancer patients. *Soc Sci Med* 40(4):517–528
 33. Mosher CE, Given BA, Ostroff JS (2015) Barriers to mental health service use among distressed family caregivers of lung cancer patients. *Eur J Cancer Care (Engl)* 24(1):50–59
 34. Northouse LL, Mood DW, Schafenacker A, Kalemkerian G, Zalupski M, Lorusso P, et al. (2013) Randomized clinical trial of a brief and extensive dyadic intervention for advanced cancer patients and their family caregivers. *Psycho-Oncology* 22(3):555–563
 35. Regan TW, Lambert SD, Girgis A, Kelly B, Kayser K, Turner J (2012) Do couple-based interventions make a difference for couples affected by cancer?: a systematic review. *BMC Cancer* 12(1):279
 36. Duggleby W, Wright K, Williams A, Degner LF, Cammer A, Holtslander L (2007) Developing a living with hope program for caregivers of family members with advanced cancer. *J Palliat Care* 23(1):24–31
 37. Friðriksdóttir N, Saevarsdóttir T, Halfdánardóttir SÍ, Jónsdóttir A, Magnúsdóttir H, Olafsdóttir KL, et al. (2011) Family members of cancer patients: needs, quality of life and symptoms of anxiety and depression. *Acta Oncol (Madr)* 50(2):252–258
 38. Wadhwa D, Burman D, Swami N, Rodin G, Lo C, Zimmermann C (2013) Quality of life and mental health in caregivers of outpatients with advanced cancer. *Psycho-Oncology* 22(2):403–410
 39. Aldwin CM, Revenson TA (1987) Does coping help? A reexamination of the relation between coping and mental health. *J Pers Soc Psychol* 53(2):337–348
 40. Lund L, Ross L, Petersen MA, et al. (2014) Cancer caregiving tasks and consequences and their associations with caregiver status and the caregiver's relationship to the patient: a survey. *BMC Cancer* 14:1–13