European Journal of Oncology Nursing 43 (2019) 101669

Contents lists available at ScienceDirect

European Journal of Oncology Nursing

journal homepage: www.elsevier.com/locate/ejon

Profiles of caregivers most at risk of having unmet supportive care needs: Recommendations for healthcare professionals in oncology

Anne-Sophie Baudry[a,*], Laurence Vanlemmens[b], Amelie Anota[c,d], Alexis Cortot[e], Guillaume Piessen[f], Veronique Christophe[a,d,**]

[a] Univ. Lille, UMR CNRS 9193, SCALab, Sciences Cognitives et Sciences Affectives, Rue du Barreau, BP 60149, 59653, Villeneuve d'Ascq cedex, France
[b] Centre Oscar Lambret - Département de Sénologie, BP 307, F-59020, Lille cedex, France
[c] Methodology and Quality of Life in Oncology Unit (INSERM UMR 1098), University Hospital of Besançon, Besançon, France
[d] French National Platform Quality of Life and Cancer, Besançon, France
[e] Univ. Lille, Department of Thoracic Oncology, Albert Calmette University Hospital, Lille, France
[f] Univ. Lille, Department of Digestive and Oncological Surgery, Claude Huriez University Hospital, F-59000, Lille, France

ARTICLE INFO

Keywords:
Anxiety
Cancer
Caregiver
Depression
Profiles
Risks
Supportive care needs

ABSTRACT

Purpose: This study aimed to identify profiles of caregivers to cancer patients at higher risk of having at least one moderately or highly unmet supportive care need based on 1) relevant socio-demographic (e.g. age, gender) and clinical (e.g. type of cancer, phase of the cancer pathway) variables highlighted in the literature and easily identifiable in routine, and 2) caregivers' anxiety and depression symptoms.

Method: Three hundred and sixty-four main caregivers completed a questionnaire assessing their supportive care needs (SCNS-P&C-F) and anxiety and depression symptoms (HADS) during the treatment or follow-up stage of patients with digestive, breast, or lung cancer. Decision trees were used to identify profiles of caregivers with the Conditional inference Tree (CTree) technique.

Results: In our study, only the combination of three main variables was important to predict the risk of unmet supportive care needs of caregivers: anxiety and/or depression symptoms, the age of caregivers or patients, and the presence/absence of metastases. Emotional distress has the greatest impact, exceeding that of the socio-demographic and clinical variables considered in this study.

Conclusions: This study shows the importance of considering a set of variables and their combinations rather than evaluating their effects separately. Routinely assessing the anxiety and depression symptoms of caregivers using the HADS could improve the screening of caregivers at higher risk of unmet supportive care needs based on socio-demographic and clinical variables only. This study provides recommendations on how to identify caregivers at risk of unmet needs, in the context of an inability to support all caregivers.

1. Introduction

Caregivers (e.g. family members, friends, or neighbors) of cancer patients play an important role for patients as well as healthcare professionals. They may provide domestic, physical, care, psychological, and social support to patients in their daily lives and therefore become caregivers (Girgis et al., 2013a; Given et al., 2012; Oberoi et al., 2016; Williams and Bakitas, 2012). However, the transition to this role can be challenging because they are not equipped to become caregivers and to cope with the associated responsibilities (Hashemi-Ghasemabadi et al., 2016). They generally perceive it as a normal and family responsibility (Girgis et al., 2013a; Shaw et al., 2013) and give priority to the cancer patient, to the detriment of their own support needs (Hashemi-Ghasemabadi et al., 2016; Shaw et al., 2013).

Their involvement and subsequent difficulties can lead to a deterioration in the caregivers' quality of life and to health problems (Girgis et al., 2013a; Hashemi-Ghasemabadi et al., 2016; Northouse et al., 2012). In fact, they report supportive care needs, which may not be

* Corresponding author. Université de Lille, Domaine Universitaire du Pont de Bois, UMR CNRS 9193 SCALab, Rue du Barreau, BP 60149, F-59653, Villeneuve d'Ascq cedex, France.
** Corresponding author. Université de Lille, Domaine Universitaire du Pont de Bois, UMR CNRS 9193 SCALab, Rue du Barreau, BP 60149, F-59653, Villeneuve d'Ascq cedex, France.
E-mail addresses: anne-sophie.baudry@univ-lille.fr (A.-S. Baudry), l-vanlemmens@o-lambret.fr (L. Vanlemmens), aanota@chu-besancon.fr (A. Anota), a.cortot@chru-lille.fr (A. Cortot), g.piessen@chru-lille.fr (G. Piessen), veronique.christophe@univ-lille.fr (V. Christophe).

https://doi.org/10.1016/j.ejon.2019.09.010
Received 8 April 2019; Received in revised form 24 September 2019; Accepted 29 September 2019

met, related to care and information (e.g. accessing information about the medical situation, having opportunities to discuss concerns with professionals, reducing stress in the patient), psychological and daily support (e.g. managing concerns about the recurrence of cancer or feelings about death and dying, balancing the patients' needs and their own needs), professional and social security (e.g. obtaining financial/government support, access to legal services), and family support (e.g. better communication with patient and family, better support from family) (Baudry et al., 2019; Lambert et al., 2012).

Some caregivers are at greater risk of having unmet supportive care needs (USCN), which contributes to their negative experience and adjustment difficulties. Overall, women, young people, and non-spouse/partner caregivers in metastatic cancer, palliative care, and caregivers of younger patients have more USCN (Chen et al., 2016; Friðriksdóttir et al., 2011; Heckel et al., 2015; Lambert et al., 2012; Lund et al., 2015; Soothill et al., 2001). The tumor localization and the phases of the cancer pathway (e.g. active treatments, follow-up) may also influence the USCN of caregivers (Balfe et al., 2016; Campbell et al., 2009; Girgis et al., 2013b; Heckel et al., 2015; Kim et al., 2010; Kim and Given, 2008; Sklenarova et al., 2015a, 2015b). In fact, caregivers of patients with lung or digestive cancer report more USCN (Girgis et al., 2013b; Lund et al., 2015; Sklenarova et al., 2015a, 2015b) and the unmet needs decrease over time (Girgis et al., 2013b; Kim et al., 2010; Lambert et al., 2018).

Caregivers with anxiety and depression symptoms also report more USCN at each stage of the cancer pathway (Buscemi et al., 2010; Friðriksdóttir et al., 2011; Girgis et al., 2013b; Heckel et al., 2015; Lambert et al., 2018; Oberoi et al., 2016; Sklenarova et al., 2015a, 2015b). Importantly, because a significant proportion of caregivers report high anxiety (16–56%) and depression (10–53%) symptoms (Friðriksdóttir et al., 2011; Girgis et al., 2013a; Lim et al., 2013; Oberoi et al., 2016; Rhee et al., 2008), a large number of caregivers might be particularly at risk of having unmet needs, leading to a poor quality of life or health disorders.

The literature suggests the variables (e.g. age, gender, educational level, caregiver type, localization of cancer, type of cancer, phase of the cancer pathway, treatments received, emotional distress) that may be important in satisfying the supportive care needs of informal caregivers in the cancer context. However, it is not known how the combination or interaction of these variables may influence needs. Since health professionals sometimes need to support informal caregivers, and assess their capacities and difficulties, it is essential to identify homogeneous subgroups of informal caregivers who are more at risk of having unmet needs due to a combination of their individual characteristics.

Thus, this study aimed to identify the profiles of caregivers - a common practice in epidemiology and public health (Lemon et al., 2003; Venkatasubramaniam et al., 2017) - at greater risk of having at least one moderately or highly USCN based on 1) relevant socio-demographic and clinical variables highlighted in the literature as well as easily identifiable in clinical routine, and 2) anxiety and depression symptoms (also referred to as "emotional distress" in the present paper).

2. Method

This study was a descriptive, by self-report questionnaire, and cross-sectional survey. The inclusion criteria for participants were to be aged over 18 years and designated as the primary caregiver by patients with a first cancer during their active treatment or follow-up until one year after the end of the treatment, and without a psychological or physical inability to answer the questionnaire. The primary caregiver was considered the caregiver who provided the most support to the patient on a daily basis from the patient's point of view.

The study was explained and proposed to patients during a consultation in 3 cancer hospital departments during a period of 18 months. After the patients had identified their primary caregiver and given their informed consent, the study was explained and proposed to the designated caregiver. After giving their consent, the caregiver received a questionnaire at the hospital or through the patient to complete and return to the care center. This study was performed in accordance with the Declaration of Helsinki and with the positive approval of the University Ethics Committee (2015-3-S35).

3. Measures

3.1. Socio-demographic and clinical data

Data relating to patients (e.g. age, gender) and their clinical situation (e.g. type of cancer, stage of the cancer pathway) were extracted from the patients' medical records with their consent. Caregivers completed a questionnaire assessing their own socio-demographic variables (e.g. age, gender, education level).

3.2. SCNS-P&C-F (supportive care needs survey for partners and Caregivers, Baudry et al., 2019)

This scale is composed of 41 five-point items (i.e. 1 = No need, 2 = Satisfied need, 3 = Low unmet need, 4 = Moderate unmet need, 5 = High unmet needs). The validation showed a factorial structure with 4 dimensions, enabling 4 scores of supportive care needs to be generated according to the type of needs: 1) Health Care Service and Information Needs, 2) Emotional and Psychological Needs, 3) Professional and Social Security Needs, and 4) Communication and Family Support Needs. In accordance with the validation of the SCNS-P &C-F (Baudry et al., 2019), the items were re-scored on a 4-point scale (i.e. 1 to 4) such that response 1 corresponds to no need or satisfied need and responses 2, 3, and 4 correspond to low, moderate, and high unmet needs, respectively. Two types of scores can be considered for the subscales: 1) the mean of corresponding items (i.e. from 1 to 4), such that a high score indicates a high level of USCN; 2) the number and frequency of USCN, as often considered in the literature (e.g. Girgis et al., 2013b; Heckel et al., 2015; Lambert et al., 2012; Sklenarova et al., 2015a, 2015b).

3.3. HADS (hospital anxiety and depression Scale, Zigmond, & Snaith, 1983; Razavi et al., 1989)

This scale is composed of 14 four-point items (i.e. ranging from 0 to 3) and enables one score of anxiety symptoms (7 items) and one score of depression symptoms (7 items) to be generated. A high score on the 0–21 scale (i.e. the sum of corresponding items) corresponds to a high level of anxiety or depression. A score ≥ 11 could indicate a clinical level of anxiety or depression, although the optimal cut of scores for anxiety and depression in a cancer context has still not been decided.

4. Statistical analysis

A descriptive of baseline sociodemographic and clinical characteristics of the patients and caregivers was done. Qualitative variables were described using number and percentages. Quantitative variables were described using mean with standard deviation and median with range.

Decision trees were used to identify the profiles of caregivers at higher risk of USCN by combining individual and clinical characteristics with a recursive partitioning. Decision trees explore the different types of relationships between variables that identify subgroups sharing the same level of outcome (Lemon et al., 2003; Venkatasubramaniam et al., 2017). This technique may be better adapted than traditional regression, which estimates average effects. It is more flexible and provides better accuracy in the prediction of outcomes (i.e. Mean Squared Error) by identifying the homogeneous subgroups of a population (Venkatasubramaniam et al., 2017). Moreover, it selects the best

variables in order of importance with reference to the outcome, even when faced with potential multicollinearity problems, and the best cut-off point of these variables estimated by the model to predict the outcome. The Conditional inference Tree (CTree) technique (partykit package of R) (Hothorn and Zeileis, 2015) was chosen based on recommendations (Venkatasubramaniam et al., 2017). This technique uses statistical hypothesis tests to split the sample; it demonstrates good predictive accuracy and a simplified construction and interpretation of trees. A sample size of 250 can be considered acceptable.

Decision trees were constructed for each type of supportive care need (i.e. 4 needs), which were recoded as 0 (i.e. no unmet or low need) and 1 (i.e. at least one moderately or highly unmet need), in line with the literature (e.g. Baudry et al., 2019; Girgis et al., 2013b; Heckel et al., 2015; Lambert et al., 2012; Sklenarova et al., 2015a, 2015b). In fact, the decision trees were developed on the different types of supportive care needs (not on the overall score) because: 1) they can lead to different difficulties and a need for intervention by different professionals (e.g. doctors, nurses, psychologists, social workers); 2) the predictors differ according to the type of USCN. The criterion of having a moderate or highly unmet need is most often considered in the literature and could be associated with a significant difficulty related to care or caregiving role and a real need for support. This maximizes clinical usefulness in a healthcare context with limited resources (Girgis et al., 2013b).

Thus, 4 decision trees were created by combining the following socio-demographic and clinical variables, highlighted in the literature as well as easily identifiable in clinical routine: caregivers' age, gender, type (e.g. spouse, child), and education level, as well as the age and gender of patients, localization of cancer (i.e. breast, digestive, or lung cancer), type of cancer (i.e. metastatic or not), phase of the cancer pathway (i.e. treatment step or follow-up), treatments received (i.e. chemotherapy, radiation therapy, hormone therapy), and the anxiety and depression symptoms of caregivers. The decision trees were based on participants without missing data.

After obtaining the profiles of caregivers for each type of supportive care need by decision trees, the profiles were constructed and compared with regard to the overall scores of USCN (i.e. 1–4 scores) using non-parametric tests (i.e. Kruskal-Wallis and pairwise comparisons using the Wilcoxon rank adjustment with the Bonferroni method). This enabled the validity of the profiles obtained to be confirmed. In particular, it was possible to verify that both the profiles at higher risk of having at least one moderately or highly unmet need and the profiles with higher unmet needs could be identified.

5. Results

5.1. Participants

Participation in the study was agreed by 423 caregivers and 59 were excluded from analyses (13.95%) due to a non-return of the questionnaire or too many missing data. The majority of the excluded participants were caregivers of patients with breast cancer (n = 41, 70.69%), without metastases (n = 38, 65.52%), and during the follow-up stage (n = 32, 55.17%).

The survey was completed by 364 caregivers aged 19–87 years (M = 58.05; SD = 13.22). The majority were women (n = 233, 64.01%), living in a couple (n = 323, 88.73%), retired (n = 184, 50.55%), and the spouse of the patient (n = 280, 76.92%). The patients were aged 25–94 years (M = 61.90; SD = 11.69) and the majority were men (n = 189, 51.92%), retired (n = 213, 58.52%), with a digestive cancer (n = 183, 50.27%), without metastases (n = 238, 65.38%), and during a follow-up stage (n = 193, 53.02%). A detailed sample description is provided in Table 1.

Table 1
Socio-demographic and clinical characteristics of the sample (N = 364).

	n	%
Caregivers		
Age		
Mean (SD)	58.05 (13.22)	
Median (min-max)	61.00 (19–87)	
Gender		
Men	131	35.99
Women	233	64.01
Education		
≤ High school	254	69.78
≥ College	89	24.45
Missing data	21	5.77
Caregiver type		
Partner	280	76.92
Child	48	13.19
Sister/Brother	13	3.57
Mother/Father	10	2.75
Friend	8	2.20
Other	5	1.37
Patients		
Age		
Mean (SD)	61.90 (11.69)	
Median (min-max)	63.50 (25–94)	
Gender		
Men	189	51.92
Women	175	48.08
Cancer type		
Breast	122	33.52
Digestive	183	50.27
Lung	59	16.21
Metastases		
No	238	65.38
Yes	125	34.34
Missing data	1	.28
Stage of the cancer pathway		
Undergoing treatment	171	46.98
Follow-up	193	53.02
Treatment received		
Surgery	219	60.16
Chemotherapy	315	86.54
Radio/Radiation therapy	107	29.40
Hormone therapy	39	10.71

Table 2
Description of the scores of SCNS-P&C-F and HADS scales.

	Mean (SD)	Median (Min-Max)
HADS		
Anxiety	10.00 (4.47)	10.00 (0–21)
Depression	6.14 (3.87)	6.00 (0–19)
SCNS-P&C-F - USCN		
Health care and information	1.69 (.77)	1.39 (1.00–3.89)
Emotional and psychological	1.66 (.68)	1.50 (1.00–4.00)
Professional and Social Security	1.40 (.62)	1.00 (1.00–4.00)
Communication and Family Support	1.48 (.79)	1.00 (1.00–4.00)

5.2. Anxiety, depression, and USCN

The scores of participants for the SCNS-P&C and HADS scales are presented in Table 2. The results showed that 45% of the sample could reveal clinical levels of anxiety (i.e. score ≥11) and 15% of the sample could reveal clinical levels of depression (i.e. score ≥11). Finally, 51% of the caregivers reported at least one moderately or highly USCN related to care and information needs and to emotional and psychological needs, compared with 26% for professional support needs and 24% for family support needs.

Table 3
Description and comparison of the caregiver profiles based on the Conditional inference Tree (CTree).

	Description of profiles	Risk of having at least one moderately or highly unmet need	Unmet needs Mean (SD)
Care and information			
Profile 1 - smaller risk (18.39% of the sample)	Anxiety ≤ 5	23%	1.22 (.38)[a]
Profile 2 - greater risk (39.85%)	Anxiety > 5, Patient age ≤ 61	82%	1.94 (.78)[b]
Profile 3 - medium risk (26.44%)	Anxiety > 5, Patient age > 61 with no metastatic cancer	45%	1.59 (.79)[c]
Profile 4 - greater risk (15.32%)	Anxiety > 5, Patient age > 61 with a metastatic cancer	75%	1.78 (.77)[b,c]
Kruskal-Wallis p-value			53.18, $p < .001$
Emotional and psychological			
Profile 1 - smaller risk (19.05% of the sample)	Anxiety ≤ 5	21%	1.19 (.33)[a]
Profile 2 - smaller risk (9.92%)	Anxiety > 5, Depression ≤ 2	40%	1.40 (.52)[a]
Profile 3 - greater risk (38.09%)	Anxiety > 5, Depression > 2, Caregiver age ≤ 59	88%	2.16 (.71)[b]
Profile 4 - medium risk (32.14%)	Anxiety > 5, Depression > 2, Caregiver age > 59	61%	2.22 (.85)[b]
Kruskal-Wallis p-value			65.33, $p < .001$
Professional and social security			
Profile 1 - smaller risk (25.72% of the sample)	Depression ≤ 3	6%	1.11 (.28)[a]
Profile 2 - medium risk (21.38%)	Depression > 3, Caregiver age ≤ 50	58%	1.63 (.68)[b]
Profile 3 - smaller risk (28.62%)	Depression > 3, Caregiver age > 50, Anxiety ≤ 11	18%	1.31 (.62)[a,c]
Profile 4 - medium risk (24.27%)	Depression > 3, Caregiver age > 50, Anxiety > 11	40%	1.57 (.71)[b,c]
Kruskal-Wallis p-value			43.78, $p < .001$
Family support			
Profile 1 - smaller risk (45.52%)	Depression ≤ 11, Anxiety ≤ 9	9%	1.21 (.54)[a]
Profile 2 - smaller risk (43.79%)	Depression ≤ 11, Anxiety > 9	31%	1.61 (.86)[b]
Profile 3 - medium risk (10.69% of the sample)	Depression > 11	64%	2.10 (.98)[c]
Kruskal-Wallis p-value			43.01, $p < .001$

The indices a, b, c correspond to the post-hoc comparisons between each profile for the different variables, $p < .05$.

5.3Description of the profiles obtained for each type of supportive care need

5.3.1. Profiles for supportive care needs related to care and information (Fig. 1 a and Table 3)

The model defined four caregiver profiles based on the anxiety of caregivers, age of patients (i.e. 61 years), and the presence or absence of metastases. The caregivers most at risk of having at least one moderately or highly unmet care and information need were those with an anxiety score greater than 5 and caring for patients aged 61 years or less (i.e. profile 2) with a risk of 82% estimated by the model. They represented 39.85% of the total sample. More precisely, the caregivers of profile 1 (anxiety ≤ 5) had less risk of having at least one moderately or highly unmet need but also reported fewer USCN than the others.

5.3.2. Profiles for supportive care needs related to emotional and psychological support (Fig. 1 b and Table 3)

The model defined four caregiver profiles based on the anxiety, depression, and age of caregivers (i.e. 59 years). The caregivers most at risk of having at least one moderately or highly unmet emotional and psychological need were those with an anxiety score greater than 5, a depression score greater than 2, and aged 59 years or less (i.e. profile 3), with a risk of 88%. They represented 38.09% of the total sample. Overall, the two highest risk profiles (i.e. profiles 3 and 4) also reported more USCN than the other two profiles with lower risks (i.e. profiles 1 and 2).

5.3.3. Profiles for supportive care needs related to professional and social security (Fig. 1 c and Table 3)

The model defined four caregiver profiles based on the depression, age (i.e. 59 years), and anxiety of caregivers. The caregivers most at risk of having at least one moderately or highly unmet professional and social security need were those with a depression score greater than 3 and aged 50 years or less (i.e. profile 2). They represented 21.38% of the total sample. Overall, the two highest risk profiles (i.e. profiles 2 and 4) also reported more USCN than the other two profiles with lower risks (i.e. profiles 1 and 3).

5.3.4. Profiles for supportive care needs related to family communication and support (Fig. 1 d, Table 3)

The model defined three caregiver profiles based on the depression and anxiety of caregivers. The caregivers most at risk of having at least one moderately or highly unmet family support need were those with a depression score greater than 11 (i.e. profile 3). They represented 10.69% of the total sample. The profile with higher risks (i.e. profile 3) also showed greater unmet needs than the second (i.e. profile 2), which showed greater unmet needs than the profile with smaller risks (i.e. profile 1).

5.4. Discussion-conclusion

The objective of this study was to define the profiles of caregivers at higher risk of having at least one moderately or highly USCN requiring professional intervention. Decision trees based on the emotional distress of caregivers and socio-demographic and clinical variables showed different profiles at risk of unmet needs according to the type of supportive care needs predicted. Overall, the comparisons of profiles obtained in terms of unmet needs confirmed their validity.

The scores of USCN of the participants in this study are lower than those of the French validation (Baudry et al., 2019). They reported low means of dissatisfaction but the majority reported at least one USCN related to health system care and information and emotional and psychological support. The means of anxiety and depression symptoms are congruent with the literature i.e. between 16 and 56% of caregivers with anxiety and between 10 and 53% with depression (for a review, see Girgis et al., 2013a).

By combining the risk factors highlighted in the literature, we showed that only the combination of three variables is important in the satisfaction of supportive care needs: the anxiety and depression symptoms of caregivers, the age of caregivers or patients, and the presence or absence of metastases. This confirms in part the results reported in the literature (Lambert et al., 2012) but shows that, depending on the type of supportive care needs, these variables have more or less impact and their combination is crucial.

Emotional distress has the greatest impact, exceeding that of the

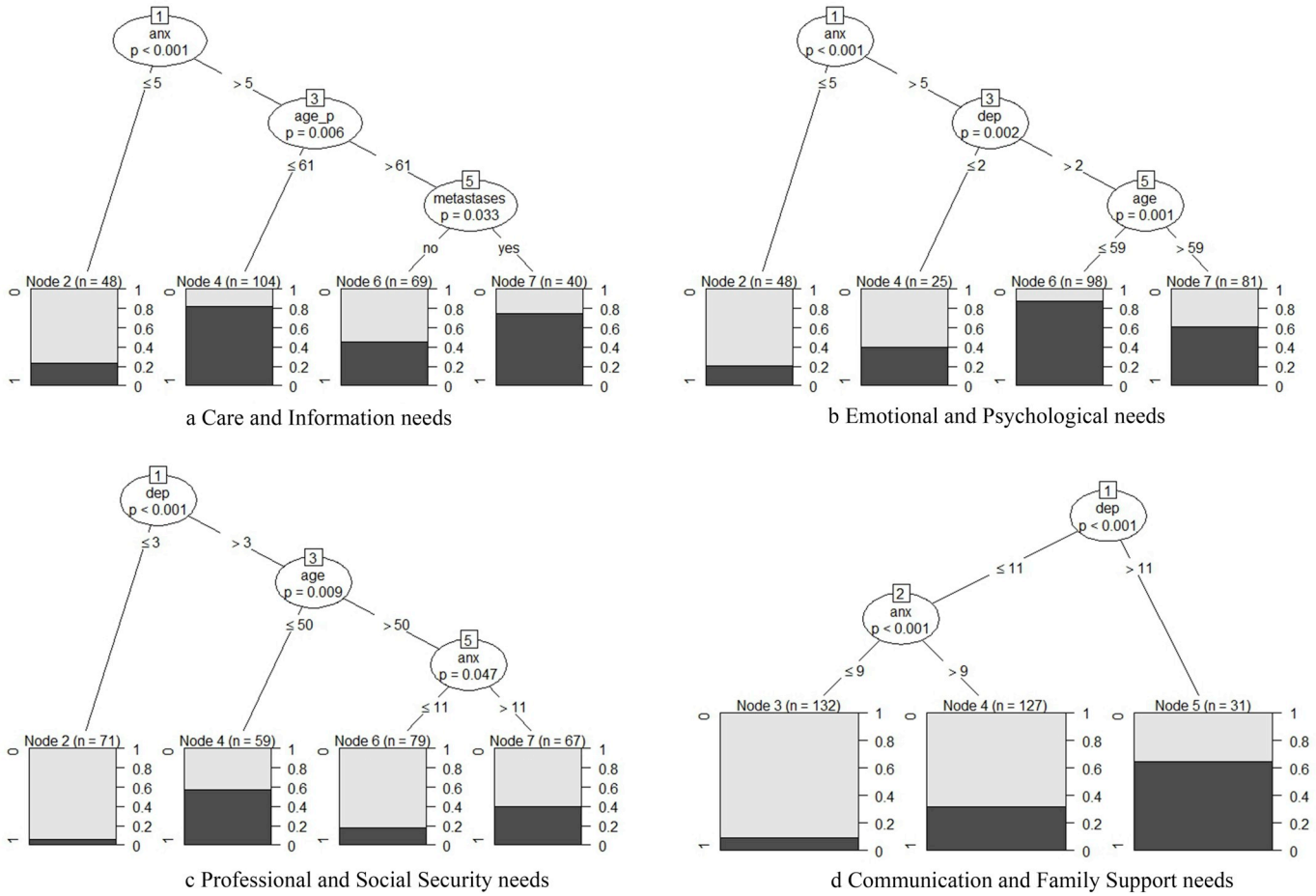

Fig. 1. Conditional inference Tree (CTree) analysis to determine individual and clinical risk factors for having at least one moderate or high unmet needs (0 = no need or low needs in grey, 1 = at least one moderate or high unmet need in black) for each type of supportive care needs related to Care and Information (n = 261) (Fig. 1a), Psychological and Emotional dimension (n = 252) (Fig. 1b), Professional and Social Security (n = 276) (Fig. 1c), and Communication and Family Support (n = 290) (Fig. 1d). anx. = anxiety, dep = depression, age_p = age of patient, age = age of caregiver.

socio-demographic and clinical variables considered in this study. Anxiety is the most discriminating variable for the needs related to care and information and emotional and psychological support, the two types of needs that are the most unsatisfied. In fact, in clinical routine, anxious individuals seem to need more concrete information, control over their environment, and an ability to anticipate the evolution of the disease or care. They could also need psychological support to manage their anxiety better. Conversely, depression is the most discriminating variable for the needs related to professional and social security and family communication and support. In fact, depressive individuals could tend to report needs for the support and understanding of caregivers in order to face the daily challenges related to hassles, administrative tasks, work, and social difficulties.

In particular, they may report a deterioration in social and family relationships and difficulties at work. In addition, the present study showed that low anxiety (e.g. from 5 to 9) and depression (e.g. 2 and 3) scores were sufficient to determine significantly the profiles of caregivers at high risk of unmet needs. Thus, emotional distress appears to be important in predicting and explaining the USCN of caregivers. Caregivers who report problems in regulating their emotional state may have more difficulty coping with cancer and their caregiving role and, as a result, may require more supportive care. In fact, emotional competence reduces anxiety and depression symptoms, which in turn reduce the USCN of cancer patients for instance (Baudry et al., 2018). The same processes could apply to caregivers. Their anxiety and depression symptoms may reduce the mobilization of their resources, negatively affect adjustment processes, and prevent them from benefiting from - and seeking - supportive care.

The variables related to patients influenced the profiles of caregivers at risk of having care and information USCN only, especially the patient's age and the presence or absence of metastases. The caregivers with an anxiety score of 5 or more and caring for younger patients (i.e. ≤ 61 years old) or older patients with metastatic cancer reported more risk of having at least one moderately or highly unmet care and information need (i.e. risk from 75 to 82%). Indeed, in the context of younger patients, caregivers tend to report more USCN with more problems related to interactions with professionals, quality of information, and a lack of attention (Heckel et al., 2015; Lund et al., 2015). Metastatic cancer is a particular difficult issue for professionals as well as patients and therefore caregivers, who have to navigate an uncertain situation. This uncertainty is often associated with specific support needs related to decision-making, information about death and the management of current and anticipated emotional distress, or changes in plans and an inability to plan, for example (Nissim et al., 2017). However, in this context, professionals may find it harder to take caregivers into account in the patient care, to support them and provide accurate and adequate information or solutions.

For psychological and emotional USCN, the caregiver profiles at higher risk showed the important role of the combination of anxiety and depression, followed by the age of caregivers, as expected from the literature (Lambert et al., 2012). Thus, caregivers who experience emotional distress (i.e. an anxiety score greater than 5 and a depression score greater than 2), either high or low emotional distress, are most at risk of needing additional support related to managing the impact of the

caregiving role on their lives and emotional experiences. This was reinforced for younger caregivers (i.e. aged 59 years or younger), who may be less equipped to cope with negative life events and the associated emotional experiences and have more day-to-day responsibilities (e.g. managing children at home, less stable work and financial situation) than older caregivers. As a result, they may need more support to cope with the impact of caregiving on their personal, social and professional lives.

In fact, the age of caregivers is also important, in interaction with anxiety and depression symptoms, in determining the profiles at higher risk of professional and social security USCN. These results are congruent with previous findings (Baudry et al., 2019; Girgis et al., 2011). Young caregivers (i.e. ≤ 50 years of age), probably employed and in the process of building a career, with a depression score above 3, reported more additional work-related and social security support needs. However, older caregivers with a depression score above 3 but an anxiety disorder reported the same overall level of unmet professional and social security needs, regardless of the clinical situation.

For communication and family USCN, only depression symptoms, to a greater extent, and anxiety symptoms identified at-risk profiles, reflecting difficulties in relationships with family members, with higher levels of depression and anxiety than for other profiles (i.e. a depression score of at least 11). These results confirmed that depression can have a significant negative impact on family relationships and hinder the solving of relationship problems.

Some variables, such as gender, tumor localization, treatment phase, or the type of caregiver, were not sufficiently discriminant in combination with the other variables to establish the profiles. Despite their significant individual influence on supportive care needs reported in the literature (Balfe et al., 2016; Chen et al., 2016; Friðriksdóttir et al., 2011; Heckel et al., 2015; Lambert et al., 2012; Lund et al., 2015), they were not sufficiently significant in combination with emotional distress, age, and the type of cancer. This confirms the important role of emotional processes, in interaction with age and type of cancer, in determining caregiver profiles at risk of having USCN.

5.5. Limitations

This study should be replicated to verify the generalization of the results to other samples. In fact, decision trees can be sensitive to small disruptions in the data and have problems with out-of-sample prediction. They depend on the characteristics of the sample and could yield different results on other types of caregiver samples (e.g. in terms of socio-demographic characteristics, medical situations, places of recruitment of participants). For example, the majority of women caregivers in the present study could influence the results. In fact, the literature shows that women caregivers tend to report more emotional distress than men (Girgis et al., 2013a; Li et al., 2013). However, emotional distress seems to be more important than gender in combination with the other socio-demographic and clinical variables used in this study to distinguish profiles at risk of having USCN. Future studies should replicate these analyses in specific contexts (e.g. according to the type of caregivers or the localization of cancer) and take into account other clinical and socio-demographic variables to improve the definition of caregiver profiles.

Future studies could also define the profiles of patients at risk of having USCN and take the patient-caregiver dyad more into account. Finally, it seems important to define the criterion to be predicted better, i.e. a “clinically significant” level of USCN of patients and caregivers that requires intervention.

5.6. Clinical implications

This study provides recommendations on how to identify caregivers at risk of USCN, in the context of an inability to support all caregivers. Screening based on socio-demographic (i.e. age of patients and caregivers) and clinical (i.e. metastatic cancer) data can help healthcare professionals (e.g. doctors, nurses). However, if they have the opportunity to assess anxiety and depression symptoms as well as using a short scale such as the HADS, screening could be improved. In fact, caregivers with emotional distress, even at a low level, may have more difficulties in daily life and find it harder to seek and receive support. An evaluation grid could be developed based on the variables highlighted in this study to guide professionals in screening for at-risk informal caregivers. For example, after this screening, a more in-depth assessment of their needs could be offered to them at a consultation. This would enable better screening and more personalized support for caregivers in difficulty thus avoiding the development of more serious disorders. It also seems important for healthcare professionals, especially nurses, to provide better education for patients and caregivers. Significant benefits to public health and patients could be expected.

5.7. Conclusion

In conclusion, the results of this study show that it is essential to consider a set of variables and their combinations rather than evaluating their effects separately. According to the type of supportive care needs, the combination of anxiety, depression, the age of patients and caregivers, and the presence or absence of metastases is important. Routinely assessing the anxiety and depression symptoms of caregivers using the HADS could improve the screening of caregivers at higher risk of USCN. This is especially relevant given that caregivers frequently reported anxiety and depression symptoms in this study (i.e. 45% of the sample revealed clinical levels of anxiety and 15% of depression) as well as in the literature (Girgis et al., 2013a). An easy-to-use digital application to calculate the risks of USCN could be created. Finally, it seems beneficial to consider the emotional processes that contribute to the satisfaction of the supportive care needs of caregivers in future health models and studies.

Declaration of competing interest

The authors declare that they have no conflict of interest.

Acknowledgements

This work was supported by the “Comité Nord de la Ligue Contre le Cancer”, the SIRIC ONCOLille (Grant INCa-DGOS Inserm 6041), and the “Region Hauts-de-France”.

We thank all participants of the study, all the investigators and Clinical Research Associates, and the Northwest Data Center (CTD-CNO), acknowledged for managing the data. It is supported by grants from the French National League Against Cancer (LNC) and the French National Cancer Institute (INCa). The authors also wish to thank Delphine Grynberg for her assistance in proofreading the manuscript.

References

Balfe, M., O'Brien, K., Timmons, A., Butow, P., O' Sullivan, E., Gooberman-Hill, R., Sharp, L., 2016. The unmet supportive care needs of long-term head and neck cancer caregivers in the extended survivorship period. J. Clin. Nurs. 25, 1576–1586. https://doi.org/10.1111/jocn.13140.

Baudry, A.-S., Anota, A., Bonnetain, F., Mariette, C., Christophe, V., 2019. Psychometric validation of the French version of the supportive care needs survey for partners and caregivers of cancer patients. Eur. J. Cancer Care 28, e12896. https://doi.org/10.1111/ecc.12896.

Baudry, A.-S., Lelorain, S., Mahieuxe, M., Christophe, V., 2018. Impact of emotional competence on supportive care needs, anxiety and depression symptoms of cancer patients: a multiple mediation model. Support. Care Cancer 26, 223–230. https://doi.org/10.1007/s00520-017-3838-x.

Buscemi, V., Font, A., Viladricht, C., 2010. Focus on relationship between the caregivers unmet needs and other caregiving outcomes in cancer palliative care. Psicooncología 7, 109–125.

Campbell, H.S., Sanson-Fisher, R., Taylor-Brown, J., Hayward, L., Wang, X.S., Turner, D., 2009. The cancer support person's unmet needs survey: psychometric properties. Cancer 115, 3351–3359.

Chen, S.-C., Chiou, S.-C., Yu, C.-J., Lee, Y.-H., Liao, W.-Y., Hsieh, P.-Y., Jhang, S.-Y., Lai, Y.-H., 2016. The unmet supportive care needs-what advanced lung cancer patients' caregivers need and related factors. Support. Care Cancer 24, 2999–3009.

Friðriksdóttir, N., Sævarsdóttir, Þ., Halfdánardóttir, S.Í., Jónsdóttir, A., Magnúsdóttir, H., Ólafsdóttir, K.L., Guðmundsdóttir, G., Gunnarsdóttir, S., 2011. Family members of cancer patients: needs, quality of life and symptoms of anxiety and depression. Acta Oncol. 50, 252–258.

Girgis, A., Lambert, S., Johnson, C., Waller, A., Currow, D., 2013a. Physical, psychosocial, relationship, and economic burden of caring for people with cancer: a review. J. Oncol. Pract. 9, 197–202.

Girgis, A., Lambert, S., Lecathelinais, C., 2011. The supportive care needs survey for partners and caregivers of cancer survivors: development and psychometric evaluation. Psycho Oncol. 20, 387–393. https://doi.org/10.1002/pon.1740.

Girgis, A., Lambert, S., McElduff, P., Bonevski, B., Lecathelinais, C., Boyes, A., Stacey, F., 2013b. Some things change, some things stay the same: a longitudinal analysis of cancer caregivers' unmet supportive care needs. Psycho Oncol. 22, 1557–1564.

Given, B.A., Given, C.W., Sherwood, P.R., 2012. Family and caregiver needs over the course of the cancer trajectory. J. Support. Oncol. 10, 57–64. https://doi.org/10.1016/j.suponc.2011.10.003.

Hashemi-Ghasemabadi, M., Taleghani, F., Yousefy, A., Kohan, S., 2016. Transition to the new role of caregiving for families of patients with breast cancer: a qualitative descriptive exploratory study. Support. Care Cancer 24, 1269–1276.

Heckel, L., Fennell, K.M., Reynolds, J., Osborne, R.H., Chirgwin, J., Botti, M., Ashley, D.M., Livingston, P.M., 2015. Unmet needs and depression among carers of people newly diagnosed with cancer. Eur. J. Cancer 51, 2049–2057.

Hothorn, T., Zeileis, A., 2015. partykit: a modular toolkit for recursive partytioning in R. J. Mach. Learn. Res. 16, 3905–3909.

Kim, Y., Given, B.A., 2008. Quality of life of family caregivers of cancer survivors: across the trajectory of the illness. Cancer 112, 2556–2568. https://doi.org/10.1002/cncr.23449.

Kim, Y., Kashy, D.A., Spillers, R.L., Evans, T.V., 2010. Needs assessment of family caregivers of cancer survivors: three cohorts comparison. Psycho Oncol. 19, 573–582.

Lambert, S., Harrison, J., Smith, E., Bonevski, B., Carey, M., Lawsin, C., Paul, C., Girgis, A., 2012. The unmet needs of partners and caregivers of adults diagnosed with cancer: a systematic review. BMJ Support. Palliat. Care 2, 224–230.

Lambert, S., Hulbert-Williams, N., Belzile, E., Ciampi, A., Girgis, A., 2018. Beyond using composite measures to analyze the effect of unmet supportive care needs on caregivers' anxiety and depression. Psycho Oncol. 27 (6), 1572–1579. https://doi.org/10.1002/pon.4696.

Lemon, S.C., Roy, J., Clark, M.A., Friedmann, P.D., Rakowski, W., 2003. Classification and regression tree analysis in public health: methodological review and comparison with logistic regression. Ann. Behav. Med. 26, 172–181. https://doi.org/10.1207/S15324796ABM2603_02.

Li, Q., Mak, Y., Loke, A.Y., 2013. Spouses' experience of caregiving for cancer patients: a literature review. Int. Nurs. Rev. 22, 2399–2407. https://doi.org/10.1111/inr.12000.

Lim, S.M., Kim, H.C., Lee, S., 2013. Psychosocial impact of cancer patients on their family members. Cancer Res. Treat. 45, 226–233. https://doi.org/10.4143/crt.2013.45.3.226.

Lund, L., Ross, L., Petersen, M., Groenvold, M., 2015. The interaction between informal cancer caregivers and health care professionals: a survey of caregivers' experiences of problems and unmet needs. Support. Care Cancer 23, 1719–1733.

Nissim, R., Hales, S., Zimmermann, C., Deckert, A., Edwards, B., Rodin, G., 2017. Supporting family caregivers of advanced cancer patients: a focus group study. Fam. Relat. 66, 867–879. https://doi.org/10.1111/fare.12291.

Northouse, L., Williams, A.-L., Given, B., McCorkle, R., 2012. Psychosocial care for family caregivers of patients with cancer. J. Clin. Oncol. 30, 1227–1234. https://doi.org/10.1200/JCO.2011.39.5798.

Oberoi, D., White, V., Jefford, M., Giles, G., Bolton, D., Davis, I., Winship, I., Prince, H., Millar, J., Harrison, S., Kay, A., Hill, D., 2016. Caregivers' information needs and their "experiences of care" during treatment are associated with elevated anxiety and depression: a cross-sectional study of the caregivers of renal cancer survivors. Support. Care Cancer 24, 4177–4186.

Razavi, D., Delvaux, N., Farvacques, C., Robaye, E., 1989. Validation de la version française du HADS dans une population de patients cancéreux hospitalisés. = Validation of the French version of the Hospital Anxiety and Depression Scale (HADS) in a population of hospitalized cancer patients. Rev. Psychol. Appliquée 39, 295–307.

Rhee, Y.S., Yun, Y.H., Park, S., Shin, D.O., Lee, K.M., Yoo, H.J., Kim, J.H., Kim, S.O., Lee, R., Lee, Y.O., Kim, N.S., 2008. Depression in family caregivers of cancer patients: the feeling of burden as a predictor of depression. J. Clin. Oncol. 26, 5890–5895. https://doi.org/10.1200/JCO.2007.15.3957.

Shaw, J., Harrison, J., Young, J., Butow, P., Sandroussi, C., Martin, D., Solomon, M., 2013. Coping with newly diagnosed upper gastrointestinal cancer: a longitudinal qualitative study of family caregivers' role perception and supportive care needs. Support. Care Cancer 21, 749–756.

Sklenarova, H., Haun, M.W., Krümpelmann, A., Friederich, H.-C., Huber, J., Thomas, M., Winkler, E.C., Girgis, A., Dinkel, A., Herzog, W., Hartmann, M., 2015. Psychometric evaluation of the German version of the supportive care needs survey for partners and caregivers (SCNS-P&C-g) of cancer patients. Eur. J. Cancer Care 24, 884–897.

Sklenarova, H., Krümpelmann, A., Haun, M.W., Friederich, H., 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. https://doi.org/10.1002/cncr.29223.

Soothill, K., Morris, S.M., Harman, J.C., Francis, B., Thomas, C., McIllmurray, M.B., 2001. Informal carers of cancer patients: what are their unmet psychosocial needs? Health Soc. Care Community 9, 464–475.

Venkatasubramaniam, A., Wolfson, J., Mitchell, N., Barnes, T., JaKa, M., French, S., 2017. Decision trees in epidemiological research. Emerg. Themes Epidemiol. 14, 11. https://doi.org/10.1186/s12982-017-0064-4.

Williams, A., Bakitas, M., 2012. Cancer family caregivers: a new direction for interventions. J. Palliat. Med. 15, 775–783.

Zigmond, A.S., Snaith, R.P., 1983. The hospital anxiety and depression scale. Acta Psychiatr. Scand. 67, 361–370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x.