Original Papers

Polish Psychological Bulletin
2024, vol. 55 94–103
DOI: 10.24425/ppb.2024.150360

Monika Paleczna[1], Sebastian Zdończyk[2], Daria Rusiecka[3]

[1] *University of the National Education Commission, Cracow, Poland*
[2] *Pomeranian University in Słupsk, Słupsk, Poland*
[3] *Pleszew Medical Center, Home Hospice, Pleszew, Poland*

CORRESPONDING AUTHOR – Monika Paleczna, monika.paleczna@uken.krakow.pl

Family Assessment vs. Positive and Negative Emotions of Informal Caregivers of Oncology Patients Receiving Home-Based Palliative Care

Abstract: Some studies involving informal caregivers of oncology patients noted that family assessment is associated with their mental health. The objective of this study is to demonstrate such a dependency in relation to informal caregivers of oncology patients receiving home-based palliative care. This study is concerned with the dependency between family assessment (family cohesion, family flexibility, family communication, and satisfaction with family life) and perceived emotions, including stress. It comprised 109 Polish informal caregivers (34 men and 75 women) of patients receiving palliative care at home. The study found that satisfaction with family life was a crucial predictor of positive emotions. This means that interventions aimed at improving satisfaction with family life may simultaneously affect the psychological functioning of informal caregivers of palliative oncology patients. Such interventions may serve to improve the quality of home-based palliative care both in regard to patients and caregivers.

Keywords: *home-based palliative care, informal caregiver, family assessment, stress, emotions*

Palliative care is an important part of the healthcare system (Ciałkowska-Rysz, 2009), and informal caregivers play an essential role (Chong et al., 2023) in this type of care. This is because they undertake to fulfill many of the medical, physical, financial, and emotional needs of advanced cancer patients (Adejoh et al., 2021). Therefore, although palliative care is usually understood to mean end-of-life care, according to the definition adopted by the World Health Organization (2007), it should also include family members (Buss & Lichodziejewska-Niemierko, 2008). Informal caregivers participating in home-based palliative care deserve special attention. Among others, this is due to the positive and negative emotions they experience.

EMOTIONS IN INFORMAL CAREGIVERS

For many informal caregivers, the emotional aspects of caring, such as managing the emotions of both the patient and their own, present the greatest challenge (Mosher et al., 2013; Mosher et al., 2016). The importance of the intensity of their emotions is also reflected in the specific tools developed to measure these emotions (Limonero et al., 2023) and the therapies proposed to regulate them (Applebaum et al., 2020). The emotions experienced by patients are closely related to those experienced by their caregivers (do Nascimento et al., 2021; Mosher et al., 2016). Similarly, the mood of caregivers is related to the mood of patients (Leow & Chan, 2017; Tan et al., 2018). These dependencies lead to the formation of an intense bond within the ill person-informal caregiver dyad (do Nascimento et al., 2021; Mosher et al., 2016). Taking into consideration the emotional reactions occurring within the families of oncology patients receiving palliative care, van Oosterhout et al. (2021) concluded that the patient-caregiver dyad functions as an "emotional system" to be viewed as one whole. As the researchers point out, the elements of that system influence each other.

On the one hand, informal caregivers experience a range of negative emotions. The disease in its advanced stage, lack of its improvement and the reduced quality of life of patients contribute to their feelings of anxiety, despair, grief, anger, guilt, hopelessness, helplessness, loneliness and feelings of ineffectiveness (do Nascimento et al., 2021; Grbich et al., 2001; Harrison et al., 2021; Hashemi et al., 2018; Leow & Chan, 2017; Rodenbach et al., 2019). Informal caregivers of advanced oncology patients experience also severe stress, the so-called distress that is associated with negative emotions. Its level is connected to the level of stress experienced by the patients (Hodges et al., 2005). Guo et al. (2021) indicate that it is difficult to completely avoid stress in relations between family members in the situation of a very advanced illness of one family member and hospice care provided at home. Researchers have identified a number of factors that are a source of stress for informal caregivers of oncology patients such as: symptoms resulting from the disease (pain, loss of weight, thinness of the skin), reduced functioning of the patient, changes in relationships, difficulties in maintaining support networks, lifestyle changes, and problems related to work and finances (Cochrane et al., 2021; Stamataki et al., 2014). Additionally they also point to a lack of sufficient and timely information, a sense of uncertainty, the responsibilities of the caregiving role (such as making decisions), the lack of available services focused on the entire family or difficulties in planning and organizing particular activities (such as getting to treatment) (Taylor et al., 2021). Meanwhile, Brazil et al. (2010) include the symptoms and needs experienced by patients among the most fundamental causes of stress in informal caregivers of palliative oncology patients.

On the other hand, informal caregivers experience positive emotions and also seek them out themselves. In a study by Rodenbach et al. (2019), informal caregivers of patients with advanced disease described feelings of gratitude, fulfillment, and peace. These feelings derived from the time spent with the patients and being aware of doing everything possible to provide them with support. They also felt a sense of satisfaction from caregiving stemming from looking after their own well-being. Its source was also a sense of fulfilling the wishes of patients in their final stages of life. A sense of fulfillment and peace of mind resulted, in turn, from their attentive care. As established by Mosher et al. (2013), caregivers of cancer patients strive to maintain a positive attitude and a sense of normality. They often put the needs of the patients above their own, which is their way of dealing with their own emotions. Grbich et al. (2001) also point to a range of positive emotions experienced by caregivers of patients with advanced disease. These emotions derive from the belief that they have the opportunity to talk to the patients about crucial topics, reaffirm their love for them, or address various important issues, which would not have been possible in the event of a sudden death. A source of happiness for caregivers is knowing that they can still communicate with their loved ones. After their death, the conviction of coping with the role of a caregiver plays an important part. Informal care is also linked to a sense of being rewarded. Caregivers who are better prepared for their role and those who display more hope feel more rewarded for their responsibilities than caregivers with high levels of anxiety and those married to the patient (Henriksson et al., 2015).

CANCER AND THE PERCEPTION OF FAMILY

The consequences of cancer extend far beyond the patient. Patients themselves use terms such as “we underwent treatment” (instead of “I underwent”), and researchers refer to “we disease” as indicative of the shared experience of the entire family (Kayser et al., 2007; Vrontaras, 2018). Northouse (1989) emphasizes the importance of the ongoing assessment of family members’ adjustment to cancer. Many previously mentioned studies demonstrate that stress levels and emotional intensity in oncology patients at an advanced disease stage are related to stress levels and emotional intensity in their informal caregivers (do Nascimento et al., 2021; Hodges et al., 2005; Mosher et al., 2016). This means that the functioning of the family is changing constantly and dynamically. Certain transformations in one person can affect the other. Moreover, informal caregivers themselves indicate that one of the factors related to their mental health is the relationship with a terminally ill family member (Bayliss et al., 2023; Shield et al., 2023). Thus, the researchers underlined that the perceived family functioning is vital for the functioning of informal caregivers (Thomson et al., 2022; 2023). Therefore, growing numbers of researchers examine the relationship between cancer and the perceptions of their own families of patients and the people who are close to them. To this end, they refer to various concepts.

Some researchers rely on the dimensions highlighted by Moos (1990; Moos & Moos, 1994): cohesion (defined as a sense of family togetherness and willingness to make time for the family), expressiveness (defined as the ability to express one’s emotions to family members) and conflict (defined as openly expressed anger, as well as conflicts between family members). They demonstrated that families with more open communication (able to talk freely about financial and work issues) were characterized by greater cohesion and lower levels of conflict and established that coherence perceived by caregivers was negatively related to their sense of caregiver strain (Thomson et al., 2022; 2023). Some studies analyze the relationship between perceived family dimensions and the mental health of caregivers. It was established that the supportive families (defined by the highest scores in cohesion and expressiveness) have the highest levels of mental and physical health, and detached families (defined by the lowest cohesion and weakest conflict resolution) have the lowest (Nissen et al., 2016). Similar results were obtained by Kissane et al. (1994) and Edwards & Clarke (2004).

Most researchers analyzing the functioning of cancer patient families refer to the dimensions identified by Olson (2011): cohesion, flexibility (initially called adaptability), communication, and satisfaction with family life. According to Kotkamp-Mothes et al. (2005), perceived cohesion, adaptability, and communication influence the adaptation process of family members to a loved one's illness. Little attention has been paid to informal caregivers, with most researchers focusing on oncology patients. They pay particular attention to family cohesion or the emotional bond between family members (Olson & Gorall, 2006). Perceived family cohesion was found to improve the adjustment to disease in both pediatric patients (Van Schoors et al., 2017) and adults (Friedman et al., 1988). It also provides a protective factor against suicidal thoughts in patients (Zhou et al., 2020). The greatest emphasis was placed on family cohesion in the context of adolescent patients. Rait et al. (1992) established that the perceived level of family cohesion in adolescent cancer survivors was lower than in healthy adolescents. According to the researchers, this may be the result of the family protecting its members from additional emotional stress or from the parents' failure to recognize their children's psychological needs. Furthermore, the study confirmed that perceived family cohesion was positively associated with the mental health, self-esteem, and global competence of young people. Birgisdóttir et al. (2019) used their own family cohesion assessment tool to establish that in adolescents, the loss of a parent who had cancer was associated with perceived poor family cohesion, both during adolescence and later in early adulthood. Moreover, the researchers (Birgisdóttir et al., 2023) have demonstrated that adolescents who give family cohesion a low rating one year after losing a parent to cancer are at risk of developing symptoms of depression, anxiety, or sleep difficulties.

Family cohesion was also analyzed in the context of palliative care patients. Scholars found it to be associated with lower severity of depressive symptoms in terminal patients (Park et al., 2018). In addition, it was shown to be positively associated with a sense of meaning in life in patients in palliative care (Liu et al., 2022). Barnes (1997) assessed 30 families at two points in time: one week and four weeks after an ill family member was given home hospice care. He observed no significant changes over time in terms of family cohesion.

Another important dimension in the context of family life, as highlighted by Olson (2011), is flexibility, i.e. the quality and degree of changes occurring in systems related to leadership, the roles and rules of mutual interaction, and those resulting from negotiation processes between family members. Initially, the researcher used the term adaptability, and the focus was placed only on the possibility of changes being made and not on their actual implementation (Margasiński, 2013). Rait et al. (1992) expected adolescent cancer survivors to rate their family's adaptability lower than healthy adolescents; however, they did not confirm this hypothesis. Family flexibility (adaptability) was also studied in relation to palliative care patients. Park et al. (2018) established that patients whose families demonstrated higher levels of family adaptability were characterized by lower levels of anxiety and depression. In contrast, Barnes (1997) found that the degree of flexibility does not change significantly over several weeks following the start of home-based hospice care.

The third dimension highlighted by Olson (2011) is communication in the family, defined as positive communication skills. Phillips-Salimi et al. (2014) found that the perception of family communication by adolescents who had recently received a cancer diagnosis as weaker was related to the perception of family cohesion and adaptability as weaker by both them and their parents. Similar results were obtained for family communication as perceived by the parents. The lower the rating it received, the weaker the family cohesion and adaptability as perceived by both the parents and the adolescent. In turn, the adolescents' and the parents' assessment of family cohesion and adaptability did not demonstrate a high level of agreement. Most studies on communication in families with a cancer patient made no reference to Olson's (2011) concept. Zhang & Siminoff (2003) established that many families experience communication problems. Improper methods of communication might lead to negative consequences. Researchers found caregiver strain to be associated with communication that was based on hostility (Otto et al., 2021), with the strain being less severe in those caregivers whose families communicated more openly (Campbell-Salome et al., 2022). Other studies have found that a more positive assessment of care is associated with a more positive perception of family communication (Shin et al., 2019). Goldsmith et al. (2016) interviewed 24 dyads of cancer patient-family member. They distinguished four patterns of communication within the family: caregivers using their medical knowledge in conversations, caregivers trying to support the family by avoiding difficult conversations, caregivers willing to communicate openly on a variety of topics, and caregivers interacting with the patient to a minimal degree. A specific communication pattern was also associated with readiness to talk about dying, which was particularly low in the first, second, and fourth types.

Olson's (2011) concept also distinguishes the dimension of satisfaction with family life. This dimension is understood as the degree to which individuals within the family feel fulfilled and happy with each other. Melguizo-Garín et al. (2022) demonstrated that there was a positive correlation between satisfaction with family life and satisfaction with social support received by parents of adolescents and young adults with cancer. By comparison, Svetina and Nastran (2012) found that satisfaction with family life negatively predicts post-traumatic growth. However, the researchers failed to identify potential reasons for this dependency.

Based on the studies under analysis, it can be concluded that perceived family functioning is associated with the mental health of oncology patients (Van Schoors et al., 2017; Zhou et al., 2020) and informal caregivers (Edwards & Clarke, 2004; Nissen et al., 2016; Otto et al., 2021; Thomson et al., 2022). In contrast, little attention has been paid to the families of the patients receiving home-based palliative care. The relationship of perceived family functioning with the mental health of patients in palliative care has admittedly been analyzed (Park et al., 2018), but there has only been limited coverage of this issue in relation to informal caregivers (Barnes, 1997). Taking into consideration the potential association of perceived family functioning with an individual's mental health, it is worth asking whether such an association also exists in relation to informal caregivers of palliative care patients. The intensity of positive and negative emotions, including distress, seems to be of particular importance. Although stress and emotions are strongly related, due to the fact that stress is a specific phenomenon among informal caregivers of patients receiving home palliative care, it was analyzed separately from negative emotion. Three research hypotheses were posed:

1. Negative predictors of stress in informal caregivers of oncology patients receiving home-based palliative care include: a) family cohesion, b) family flexibility, c) family communication, and d) satisfaction with family life.
2. Negative predictors of negative emotions in informal caregivers of oncology patients receiving home-based palliative care include: a) family cohesion, b) family flexibility, c) family communication, and d) satisfaction with family life.
3. Positive predictors of positive emotions in informal caregivers of oncology patients receiving home-based palliative care include: a) family cohesion, b) family flexibility, c) family communication, and d) satisfaction with family life.

METHOD

Participants

The research presented in this article is part of a larger research project aimed at adapting and validating a questionnaire intended for the assessment of the functioning of informal caregivers. A total of 150 informal caregivers aged between 22 and 77 years *(M* = 48.7; *SD* = 14.6), including 44 men and 106 women, participated in the project. For the purposes of this study, it was necessary to convert the scores obtained using the Family Rating Scale (*Skala Oceny Rodziny*) (Margasiński, 2013) into a sten range. Currently, norms are available for husbands, wives, sons, and daughters. Therefore, this study included data from 109 individuals aged between 22 and 77 years *(M* = 50.0; *SD* = 13.9), including 34 men and 75 women, in such a relationship with the patient. As many as 34 respondents cared for their mother, 31 for their father, 27 for their husband, and 17 for their wife. People cared for by informal caregivers (50 men and 59 women) were between 25 and 96 years old *(M* = 66.7; *SD* = 13.3) and received home-based palliative care. Informal caregivers had been in their role for at least two weeks. Participation in the study was voluntary and anonymous, and each participant received an Empik store voucher worth PLN 25. Information about the project was provided by psychologists working in home hospices in various cities in Poland.

Tools

Skala Uczuć Pozytywnych i Negatywnych SUPIN – which is the Polish adaptation (Brzozowski, 2010) of the Positive and Negative Affect Schedule (PANAS) (Watson et al., 1988). This tool is used to assess the intensity of positive and negative emotions. It consists of two scales: the Positive Affect Scale and the Negative Affect Scale. Each scale comprises 10 statements (e.g. nervous), which the study participants rate on a scale from 1 *(very slightly or not at all*) to 5 *(extremely*). Between 10 and 50 points can be obtained on each scale. The higher the score obtained on each scale, the greater the intensity of the emotion in question. The Cronbach's alpha reliability index in validation studies, dependent on the version and type of sample, ranged from .73 to .95. In this study, it was .93 for the Negative Affect Scale and .90 for the Positive Affect Scale, respectively.

Skala Odczuwanego Stresu PSS-10 – which is the Polish adaptation (Juczyński & Ogińska-Bulik, 2009) of the Perceived Stress Scale (PSS) (Cohen et al., 1983). This tool is used to measure the intensity of stress. The study consists of 10 questions (e.g. *In the last month, how often have you been able to control irritations in your life?*) rated on a scale from 0 *(never*) to 4 *(very often*). The score is assessed on a scale from 0 to 40. The higher the score, the more intense the stress of the respondent. In the research on the Polish adaptation of this tool, Cronbach's alpha reliability index for this scale was .90, and in the current study, it was .84.

Skale Oceny Rodziny SOR – which is the Polish adaptation (Margasiński, 2013) of the Flexibility and Cohesion Evaluation Scales (FACES-IV) (Olson, 2011). This tool is used to assess family functioning. It consists of eight scales: balanced cohesion (7 items; e.g. "Family members are involved in each other's lives"); balanced flexibility (7 items; e.g. "Our family tries new ways of dealing with problems"); disengagement (7 items; e.g. "We get along better with people outside our family than inside"); enmeshment (7 items; e.g. "We spend too much time together"); rigidity (7 items; e.g. "There are strict consequences for breaking the rules in our family"); chaos (7 items; e.g. "We never seem to get organized in our family"); family communication (10 items; e.g. "Family members are satisfied with how they communicate with each other"); and family satisfaction (7 items, e.g. "The degree of closeness between family members"). Together, the scales form four dimensions. The first dimension – cohesion – is calculated by dividing the sten score obtained on the Balanced Cohesion scale by the mean sten score obtained on the Disengagement and Enmeshment scales. The second dimension – flexibility – is calculated by dividing the sten score for the Balanced Flexibility scale by the mean sten score obtained on the Rigidity and Chaos scales. The Family Communication scale is responsible for the third dimension. Its indicator is the total number of points obtained. The last scale – Family Satisfaction – is responsible for the fourth dimension. Its indicator is the total number of points obtained. The higher the score for a particular dimension, the higher the intensity of family cohesion or family flexibility, the better the assessment of family communication, and the higher the satisfaction with family life. In the studies on the Polish adaptation of this tool, Cronbach's alpha reliability indices for the Balanced Cohesion scale were as follows: .80; Balanced Flexibility: .79; Detachment: .77; Enmeshment: .70; Rigidity: .73; Chaos: .73; Family Communication: .92; Family Satisfaction: .93. In this study, the Cronbach's alpha reliability indices for the Balanced Cohesion scale were as follows: .86; Balanced Flexibility: .77; Detachment: .70; Enmeshment: .70; Rigidity: .68; Chaos: .67; Family Communication: .87; Family Satisfaction: 90. These coefficients are lower than in the validation study while still at an acceptable level. On the other hand, the dimensions that comprise the Rigidity and Chaos scales, i.e. the Flexibility dimension, should be approached with caution due to lower reliability indices. In this study, individual SOR subscales will be analyzed as separate variables: family cohesion, family flexibility, family communication and satisfaction with family life. We do not consider the overall result of the SOR questionnaire, because in informal caregivers' studies, researchers have always referred to individual dimensions of the scale.

Procedure

At the start, study participants completed documents such as the consent to participate in the study and a GDPR form. They then completed a form with their personal details. As part of the study, they completed a number of questionnaires, including: the Perceived Stress Scale (PSS-10), the Positive and Negative Affect Schedule (SUPIN), and the Flexibility and Cohesion Evaluation Scales (SOR). At the end of the study, each participant received an Empik store voucher and signed a document acknowledging its receipt. The project was implemented between April and October 2023. The study was approved by the Ethics Committee of the Institute of Psychology at Kraków's University of the National Education Commission.

RESULTS

Statistical analyses were completed using the IBM SPSS Statistics 29 software. The significance level in this chapter was assumed to be α = .05. Table 1 includes the descriptive statistics of the measured variables, and Table 2 shows the correlation matrix between variables and indicators.

Next, it was verified whether family cohesion, family flexibility, family communication, and satisfaction with family life (all indicators measured by the SOR questionnaire) predicted the intensity of positive and negative emotions (both variables measured using the

Table 1. Descriptive statistics of measured variables

Variable	N	*Mean*	*Median*	*Standard Deviation*	*Skewness*	*Kurtosis*	*Min.*	*Max.*
Positive feelings	109	31.55	33.0	8.95	-.56	.26	0	47
Negative feelings	109	23.80	22.5	10.20	.39	-.58	0	49
Stress	109	21.68	21.0	7.18	-.30	.28	0	37
Family cohesion	109	.83	.75	.47	.51	-.35	.12	2.22
Family flexibility	109	.94	.80	.46	.57	-.30	.17	2.00
Family communication	109	36.61	37.0	8.15	-.50	.20	10	50
Satisfaction with family life	109	35.77	37.0	8.87	-.46	-.59	16	50

Source: own elaboration.

Table 2. Correlation matrix between analyzed variables and indicators

Variable	1.	2.	3.	4.	5.	6.	7.
1. Positive feelings	–	.049	-.101	.033	.048	.240*	.346**
2. Negative feelings		–	.608**	-.060	-.060	.039	.141
3. Stress			-	-.328**	-.254**	-.300**	-.250**
4. Family cohesion				–	.698**	.524**	.473**
5. Family flexibility					–	.501**	.471**
6. Family communication						–	.846**
7. Satisfaction with family life							–

Note: * p < .05; ** p < .01.
Source: own elaboration.

SUPIN scale) and stress (measured using the PSS-10 scale). To test whether individual indicators of family functioning predict the emotions (positive, negative and stress) of informal caregivers, three linear regression analyzes were performed, the results of which are summarized in Table 3.

Models predicting positive emotions and the level of perceived stress matched the data well. The study obtained a statistically insignificant analysis of variance results for the negative emotion indicator as a response variable.

Family life satisfaction proved to be a significant predictor of positive emotions. A positive *Beta* value indicates an increase in positive emotions alongside an increase in the intensity of this variable. The adjusted R^2 value = 0.119, which means that the model predicted 11.9% of the dependent variable's variance.

The analysis of the level of perceived stress as a response variable, although found to be statistically significant in the whole model fit test, showed that none of the introduced predictors significantly predicted the intensity of the dependent variable. This was most likely caused by the presence of moderate collinearity between the predictors (the VIF value for the individual predictors was between 2 and 4).

DISCUSSION

The aim of this study was to establish a dependency between the family assessment by informal caregivers of home-based palliative patients and the severity of their positive and negative emotions, including stress. The study posed three research hypotheses. These were based on the findings of previous research stating that a positive assessment of one's family promotes the mental health of patients and their caregivers (Edwards & Clarke, 2004; Kissane et al., 1994; Nissen et al., 2016; Thomson et al., 2022;). It must be reiterated that the flexibility dimension is made up of scales with lower reliability scores, so the results obtained on this scale should be treated with caution. The research conducted to date has not directly addressed the relationship between informal caregivers' assessments of their family and their mental health indicators, such as the levels of positive and negative emotions. The aim of this study was to fill this gap. The focus was placed on informal caregivers of patients receiving home-based palliative care due to the intensity of the experienced emotions, including stress (do Nascimento et al., 2021; Guo et al., 2021; Hashemi et al., 2018; Leow & Chan, 2017; Rodenbach et al., 2019;

Table 3. Predicting positive and negative emotions and stress in informal caregivers based on an assessment of their family functioning

Response variable		***B***	***SE***	***beta***	***t***	***i***
Positive emotions	***F*(4;102) = 4.57; *p* = 0.002; $R^2adj.$ = 0,119**					
	(Constant)	19.64	3.83		5.12	**<.001**
	Family cohesion	-1.72	2.52	-.09	-.68	.496
	Family flexibility	-1.52	2.56	-.08	-.59	.554
	Family communication	-.12	.20	-.11	-.61	.543
	Satisfaction with family life	.54	.18	.53	3.05	**.003**
Negative emotions	***F*(4;102) = 1.69; *p* = 0.158; $R^2adj.$ = 0,025**					
	(Constant)	19.69	4.54		4.33	**<.001**
	Family cohesion	-4.64	2.99	-.22	-1.55	.124
	Family flexibility	3.39	3.03	.15	1.12	.266
	Family communication	-.28	.23	-.23	-1.19	.236
	Satisfaction with family life	.42	.21	.37	2.00	**.048**
Level of stress felt	***F*(4;102) = 3.99; *p* = 0.005; $R^2adj.$ = 0,101**					
	(Constant)	30.34	3.10		9.79	**<.001**
	Family cohesion	-3.61	2.04	-.24	-1.77	.079
	Family flexibility	-.06	2.07	<.01	-.03	.975
	Family communication	-.18	.16	-.20	-1.10	.274
	Satisfaction with family life	.02	.14	.03	.16	.876

Note: *B* – non-standardized regression factor; *SE* – standard error; *Beta* – standardized regression factor; *t* – Student's t-test result; *F* – analysis of variance result; $R^2adj.$ – adjusted R-square.
Source: own elaboration.

Stamataki et al., 2014; Taylor et al., 2021; van Oosterhout et al. 2021).

This study was expected to demonstrate that negative predictors of stress in informal caregivers of oncology patients receiving home-based palliative care would be: a) family cohesion, b) family flexibility, c) family communication, and d) satisfaction with family life (H1). This hypothesis was not confirmed. Stress is a phenomenon experienced by most informal caregivers (Guo et al., 2021). Perhaps the way caregivers perceive their family is not related to the level of stress intensity. Previous research has indicated that sources of stress in informal caregivers include factors such as symptoms resulting from the disease or limitations in the patient's functioning (Brazil et al., 2010; Cochrane et al., 2021; Stamataki et al., 2014). These are areas that informal caregivers have little potential to influence. As a positive assessment of one's own family does not reduce the pain experienced by the patient or improve the patient's functioning, it may not be directly related to the caregivers' intensity of stress. It should be emphasized, however, that the indicator obtained with the tool used for measuring stress is defined as "the assessment of one's own life situation as stressful, i.e. unpredictable, beyond control and excessively burdensome" (Juczyński & Ogińska-Bulik, 2009, p. 20). Informal caregivers who look after the people close to them most likely have been performing this role for quite some time. They probably have a routine already in place in regard to their various duties. The situation may already be predictable for them and firmly under their control. In consequence, changes in the assessment of one's family may not necessarily be related to the perception of the situation as less/more predictable or controllable. It should be noted, however, that this project would perhaps have different results if stress had been measured with a different tool and defined in a different way. According to Carolan et al. (2015), what is still lacking is a concept explaining in a more precise way how to understand stress in families providing palliative care to patients. Another explanation for the results obtained may be a reference to the coping strategies applied by informal caregivers. It may be that informal caregivers undertake such actions to maintain the feelings of stress at current levels without raising them; however, these strategies affect the family's own assessment. For example, Parker et al. (2007) found that informal caregivers want to negotiate the amount and extent of information they receive regarding life expectancy or dying. Similar observations were made by Goldsmith et al. (2016), who distinguished families in which caregivers avoid difficult conversations. Such an approach may result in a sense of weakened communication within the family (e.g. avoidance of difficult subjects to avoid key information) while not exacerbating the levels of stress that might occur during such a conversation. Such a situation would cause a change in the perception of one's family; however, the levels of stress would not change. This can explain the lack of correlation between the perception of the family and the level of stress.

The researchers conducting this study expected that the negative predictors of negative emotions in informal caregivers of oncology patients receiving home-based palliative care would include: a) family cohesion, b) family flexibility, c) family communication, and d) satisfaction with family life (H2). This hypothesis was not confirmed. Past studies have found that informal caregivers experience a range of negative emotions (Harrison et al., 2021; Hashemi et al., 2018; Leow & Chan, 2017). It is possible that they are caused by factors other than those related to family assessment. Researchers indicate that the sources of emotions that are unwanted by informal caregivers include the following: the awareness of the incurability of the disease, being a witness to a loved one's pain and suffering, lack of sleep, difficulties with coping with the current situation, unwanted life changes (Hashemi et al., 2018), the potential of making a mistake (Harrison et al., 2021), the awareness of a relative dying or different approaches to situations requiring decision-making (Rodenbach et al., 2019). Most of these factors do not appear to be directly related to the emotional bond between family members (cohesion), the changes taking place within the family system (flexibility), the ability to communicate positively (communication), or the extent to which family members feel fulfilled and happy with each other (satisfaction with family life). For this reason, a simple correlation between the perception of the family and the intensity of negative emotions may not exist. Several studies to date have shown that diminished family functioning is associated with increased levels of depression in the relatives of patients (Birgisdóttir et al., 2023; Edwards & Clarke, 2004). Its core symptoms include a lowering of mood and feelings of sadness, i.e. negative emotions. Perhaps the aspect of family assessment is not directly related to negative emotions but to more complex mood disorders.

The researchers conducting this study also expected that the positive predictors of positive emotions in informal caregivers of oncology patients receiving home-based palliative care would include: a) family cohesion, b) family flexibility, c) family communication, and d) satisfaction with family life (H3). This hypothesis was partially confirmed. It was found that the higher the satisfaction with family life (i.e. the degree to which family members feel fulfilled and happy with each other) in informal caregivers, the higher the intensity of positive emotions (H3d). Informal caregivers experience a range of positive emotions such as gratitude, fulfillment, peace (Rodenbach et al., 2019), and happiness (Grbich et al., 2001). Previous studies have found that important sources of these feelings are situations and events that are controllable by them, such as time spent with their loved ones, a sense of fulfillment in relation to the wishes of patients at the end of their lives (Rodenbach et al., 2019), or the opportunity to reaffirm one's love for the patient (Grbich et al., 2001). The same factors can be directly related to a positive assessment of one's family. In view of this, it seems that satisfaction with family life is a vital predictor of positive emotions in informal caregivers. This means that it is extremely important to nurture relationships between members of families providing home-based palliative care. Maintaining them is not easy, given the new role that the caregivers have undertaken (Thana et al., 2021). It should be highlighted that in this study, satisfaction with family life was assessed only by informal caregivers. Meanwhile, as was shown in another study, family perception may differ between patients and their caregivers (Phillips-Salimi et al., 2014). For this reason, it is recommended to also verify the level of family satisfaction felt by patients. In this study, the researchers did not confirm a dependency between family cohesion, family flexibility, family communication, and positive feelings in informal caregivers. Perhaps the category of positive emotions is too narrow, and it would be appropriate to look at whether family assessment is related to the overall positive functioning of caregivers. Li and Loke (2013) reviewed the literature discussing the positive aspects of the experiences of spouses caring for cancer patients. They determined that these aspects included an enhanced relationship with the caregiver, a sense of being rewarded, a sense of personal growth, and a sense of personal satisfaction. It seems that Olson's dimension of cohesion (Olson, 2011) could be related to a strengthened relationship with caregivers, as this dimension is defined as an emotional bond between family members.

Perhaps the emotions and stress of informal caregivers of patients receiving home-based palliative care are related to indicators of family assessment, which have not been analyzed in this study. Previous studies have shown that the conflict dimension, for example, is related to the mental health of informal caregivers (Nissen et al., 2016).

LIMITATIONS

This study is not without its limitations. First of all, family functioning was assessed only by informal caregivers. This means that the issue under analysis has been presented from only one perspective. Getting to know the perspective of the patient would certainly be interesting and rewarding. Olson (2011; Margasiński, 2013) and other researchers studying the functioning of cancer patient families (Phillips-Salimi et al., 2014) propose the assessment of the family system as the sum of perceptions of several family members. Second, the study did not analyze the size of the families of the informal caregivers. This information is crucial in terms of the social support received and, consequently, the ability to cope with a difficult situation. Third, the reliability indices included in the flexibility dimension were lower. Fourth, the number of study participants was limited. Nonetheless, it is worth noting that researchers have obtained similar sample sizes by studying the functioning of families with members in the terminal stage of an illness (e.g. Park et al., 2018). Fifth, due to the characteristics of the family assessment tool, only those for whom the sick person was a husband/wife or father/mother could participate in the study. Meanwhile, as has been established by this project, people also play the role of informal caregivers for other relatives, which would be a worthwhile addition to the study.

CONCLUSIONS

The findings of this study establish that satisfaction with family life is a significant predictor of positive emotions in informal caregivers of patients receiving home-based palliative care. To our knowledge, our study is the first to confirm such a dependency in relation to families providing palliative care at home. The results obtained as part of this project provide important information for interdisciplinary palliative caregiving teams. Attention should be paid to the degree to which individuals within the family feel fulfilled and happy with each other. It is worthwhile to plan interventions that aim to provide families with support, as this is significant for the mental health of informal caregivers of home-based palliative care patients. The use of such interventions may contribute to the improvement of the overall quality of palliative home-based care and increase the satisfaction of both caregivers and patients. In future studies, it would be useful to broaden the perspective of family assessment to include the views of other family members, such as the patients themselves. It is also recommended to search for moderators of the demonstrated dependency. It appears that the length of the care provided may play a crucial role. Our findings suggest the need to expand the study to include other dimensions related to family functioning, such as the conflict dimension. It is also important to remember that family perceptions were measured once the cancer had already occurred. It would be worth examining whether any aspects of one's own family's perception before diagnosis constitute a protective or risk factor for the mental health of informal caregivers.

Funding

This work was supported by the the Polish League Against Cancer in Poland.

Declaration of conflicting interests

The Author(s) declare(s) that there is no conflict of interest

Research ethics

This study was approved by the Ethics Committee at the Institute of Psychology of the Pedagogical University in Krakow (approval no. 01/04/2023) on April 01, 2023.

REFERENCES

Adejoh, S. O., Boele, F., Akeju, D., Dandadzi, A., Nabirye, E., Namisango, E., Namukwaya, E., Ebenso, B., Nkhoma, K., Allsop, M. J. (2021). The role, impact, and support of informal caregivers in the delivery of palliative care for patients with advanced cancer: A multi-country qualitative study. *Palliative Medicine*, *35*(3), 552-562. https://doi.org/10.1177/026921632097492

Applebaum, A. J., Panjwani, A. A., Buda, K., O'Toole, M. S., Hoyt, M. A., Garcia, A., Fresco, D. M., Mennin, D.S. (2020). Emotion regulation therapy for cancer caregivers—an open trial of a mechanism-targeted approach to addressing caregiver distress. *Translational Behavioral Medicine*, *10*(2), 413-422. https://doi.org/10.1093/tbm/iby104

Barnes, C. S. (1997). *Cohesion, flexibility, symptom distress, and coping in hospice home care families with cancer*. Medical College of Georgia.

Bayliss, K., Shield, T., Wearden, A., Flynn, J., Rowland, C., Bee, P., .. Farquhar , M., Harris, D., Hokinson, A., Panagioti, M., Booth, M., Cotterill, D. Goodburn, L., Knipe, C., Grande, G. E. (2023). Understanding what affects psychological morbidity in informal carers when providing care at home for patients at the end-of-life (EOL): a systematic qualitative evidence synthesis. *Health and Social Care Delivery Research*. https://doi.org/10.3310/PYTR4127

Birgisdóttir, D., Bylund Grenklo, T., Nyberg, T., Kreicbergs, U., Steineck, G., Fürst, C. J. (2019). Losing a parent to cancer as a teenager: Family cohesion in childhood, teenage, and young adulthood as perceived by bereaved and non-bereaved youths. *Psycho-Oncology*, *28*(9), 1845-1853. https://doi.org/10.1002/pon.5163

Birgisdóttir, D., Grenklo, T. B., Kreicbergs, U., Steineck, G., Fürst, C. J., Kristensson, J. (2023). Family cohesion predicts long-term health and well-being after losing a parent to cancer as a teenager: A nationwide population-based study. *Plos one*, *18*(4), e0283327. https://doi.org/10.1371/journal.pone.0283327

Brazil, K., Bainbridge, D., Rodriguez, C. (2010). The stress process in palliative cancer care: a qualitative study on informal caregiving and its implication for the delivery of care. *American Journal of Hospice and Palliative Medicine®*, *27*(2), 111-116.

Brzozowski, P. (2010). Skala uczuć pozytywnych i negatywnych SUPIN. Polska adaptacja skali PANAS Davida Watsona i Lee Anny Clark. Pracownia Testów Psychologicznych Polskiego Towarzystwa Psychologicznego.

Buss, T., Lichodziejewska-Niemierko, M. (2008). Opieka paliatywna w Polsce-od idei do praktyki (również lekarza rodzinnego). *Forum Medycyny Rodzinnej*, 2 (4), 277-285.

Campbell-Salome, G., Fisher, C. L., Wright, K. B., Lincoln, G., Applebaum, A. J., Sae-Hau, M., Weiss, E. S., Bylund, C. L. (2022). Impact of the family communication environment on burden and clinical communication in blood cancer caregiving. *Psycho-Oncology*, *31*(7), 1212-1220. https://doi.org/10.1002/pon.5910

Carolan, C. M., Smith, A., Forbat, L. (2015). Conceptualising psychological distress in families in palliative care: Findings from a systematic review. *Palliative medicine*, *29*(7), 605-632. https://doi.org/10.1177/0269216315575680

Chong, E., Crowe, L., Mentor, K., Pandanaboyana, S., Sharp, L. (2023). Systematic review of caregiver burden, unmet needs and quality-of-life among informal caregivers of patients with pancreatic cancer. *Supportive Care in Cancer*, *31*(1), 31-74. https://doi.org/10.1007/s00520-022-07468-7

Ciałkowska-Rysz, A. (2009). Sytuacja i wyzwania opieki paliatywnej w Polsce. *Medycyna Paliatywna*, *1*, 22-26.

Cochrane, A., Reid, O., Woods, S., Gallagher, P., Dunne, S. (2021). Variables associated with distress amongst informal caregivers of people with lung cancer: a systematic review of the literature. *Psycho-Oncology*, *30*(8), 1246-1261. https://doi.org/OI:10.1002/pon.5694

Cohen, S., Kamarck, T., Mermelstein, R. (1983). A global measure of perceived stress. *Journal of health and social behavior*, 385-396.

Coyne, E., Heynsbergh, N., Dieperink, K. B. (2020). Acknowledging cancer as a family disease: A systematic review of family care in the cancer setting. *European Journal of Oncology Nursing*, *49*, 101841. https://doi.org/10.1016/j.ejon.2020.101841

Cui, P., Shi, J., Li, S., Getu, M. A., Wang, R., Chen, C. (2023). Family resilience and its influencing factors among advanced cancer patients and their family caregivers: a multilevel modeling analysis. *BMC cancer*, *23*(1), 623. https://doi.org/10.1186/s12885-023-11101-z

do Nascimento, E. M. A., Rodrigues, M. D. S. D., Evangelista, C. B., de Oliveira Cruz, R. A., Lordao, A. V., de Souza Batista, P. S. (2021). Emotional stress between informal caregivers of patients in palliative care/Estresse emocional entre cuidadores informais de pacientes em cuidados paliativos/Estres emocional entre los cuidadores informales de pacientes en cuidados paliativos. *Enfermagem Uerj*, *29*, NA-NA. http://dx.doi.org/10.12957/reuerj.2021.61132

Edwards, B., Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: the influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, *13*(8), 562-576. https://doi.org/10.1002/pon.773

Friedman, L. C., Baer, P. E., Nelson, D. V., Lane, M., Smith, F. E., Dworkin, R. J. (1988). Women with breast cancer: perception of family functioning and adjustment to illness. *Psychosomatic Medicine*, *50*(5), 529-540.

Goldsmith, J., Wittenberg, E., Platt, C. S., Iannarino, N. T., Reno, J. (2016). Family caregiver communication in oncology: advancing a typology. *Psycho-Oncology*, *25*(4), 463-470. https://doi.org/10.1002/pon.3862

Grbich, C., Parker, D., Maddocks, I. (2001). The emotions and coping strategies of caregivers of family members with a terminal cancer. *Journal of Palliative care*, *17*(1), 30-36. https://doi.org/10.1177/082585970101700105

Guo, J. W., Reblin, M., Tay, D. L., Ellington, L., Beck, A. C., Cloyes, K. G. (2021). Patterns of stress and support in social support networks of in-home hospice cancer family caregivers. *Journal of social and personal relationships*, *38*(11), 3121-3141.

Harrison, R., Raman, M., Walpola, R. L., Chauhan, A., Sansom-Daly, U. M. (2021). Preparing for partnerships in cancer care: an explorative analysis of the role of family-based caregivers. *BMC Health Services Research*, *21*, 1-10. https://doi.org/10.1186/s12913-021-06611-0

Hashemi, M., Irajpour, A., Taleghani, F. (2018). Caregivers needing care: the unmet needs of the family caregivers of end-of-life cancer patients. *Supportive Care in Cancer*, *26*, 759-766. https://doi.org/10.1007/s00520-017-3886-2

Henriksson, A., Carlander, I., Årestedt, K. (2015). Factors associated with feelings of reward during ongoing family palliative caregiving. *Palliative & supportive care*, *13*(3), 505-512. https://doi.org/doi:10.1017/S1478951514000145

Hodges, L. J., Humphris, G. M., Macfarlane, G. (2005). A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. *Social science & medicine*, *60*(1), 1-12. https://doi.org/10.1016/j.socscimed.2004.04.018

Juczyński, Z., Ogińska-Bulik, N. (2009). Narzędzia pomiaru stresu i radzenia sobie ze stresem (Methods to measure stress and coping). Pracownia Testów Psychologicznych.

Kayser, K., Watson, L. E., Andrade, J. T. (2007). Cancer as a" we-disease": Examining the process of coping from a relational perspective. *Families, Systems, & Health*, *25*(4), 404-418. https://doi.org/10.1037/1091-7527.25.4.404

Kissane, D. W., Bloch, S., Burns, W. I., Patrick, J. D., Wallace, C. S., McKenzie, D. P. (1994). Perceptions of family functioning and cancer. *Psycho-Oncology*, *3*(4), 259-269. https://doi.org/10.1002/pon.2960030403

Kotkamp-Mothes, N., Slawinsky, D., Hindermann, S., Strauss, B. (2005). Coping and psychological well being in families of elderly cancer patients. *Critical reviews in oncology/hematology*, *55*(3), 213-229. https://doi.org/10.1016/j.critrevonc.2005.03.006

Leow, M. Q., Chan, S. W. (2017). The challenges, emotions, coping, and gains of family caregivers caring for patients with advanced cancer in Singapore: a qualitative study. *Cancer nursing*, *40*(1), 22-30. https://doi.org/10.1097/ncc.0000000000000354

Li, Q., Loke, A. Y. (2013). The positive aspects of caregiving for cancer patients: a critical review of the literature and directions for future research. *Psycho-oncology*, *22*(11), 2399-2407. https://doi.org/: 10.1002/pon

Limonero, J. T., Maté-Méndez, J., Gómez-Romero, M. J., Mateo-Ortega, D., González-Barboteo, J., Bernaus, M., López-Postigo. M., Sirgo, A., Viel, S., Sánchez-Julve, C., Bayés, R., Gómez-Batiste, X., Tomás-Sábado, J. (2023). Family caregiver emotional distress in advanced cancer: the DME-C scale psychometric properties. *BMJ Supportive & Palliative Care*, *13*(e1), e177-e184. http://dx.doi.org/10.1136/bmjspcare-2020-002608

Liu, X., Wu, X., Cheng, Q., Ying, W., Gong, X., Lu, D., Zhang, Y., Liu, Z. (2022). Meaning in life and its relationship with family cohesion: A survey of patients with palliative care in China. *Asia-Pacific*

Journal of Oncology Nursing, *9*(11), 100118. https://doi.org/10.1016/j.apjon.2022.100118

Margasiński, A. (2013). Skale Oceny Rodziny. Polska adaptacja FACES IV – Flexibility and Cohesion Evaluation Scales Davida H. Olsona. Podręcznik. Pracownia Testów Psychologicznych Polskiego Towarzystwa Psychologicznego.

Melguizo-Garín, A., Martos-Méndez, M., Hombrados-Mendieta, I., Ruiz-Rodríguez, I. (2022). Relation between social support received and provided by parents of children, adolescents and young adults with cancer and stress levels and life and family satisfaction. *Frontiers in Psychology*, *13*, 728733. https://doi.org/10.3389/fpsyg.2022.728733

Moos, R. H. (1990). Conceptual and empirical approaches to developing family-based assessment: Resolving the case of the Family Environment Scale. *Family process*, *29*(2), 199-208. https://doi.org/10.1111/j.1545-5300.1990.00199.x

Moos, R. H., Moos, B. S. (1994). Family environment scale manual: Development, applications, research. Consulting Psychologists Press.

Mosher, C. E., Jaynes, H. A., Hanna, N., Ostroff, J. S. (2013). Distressed family caregivers of lung cancer patients: an examination of psychosocial and practical challenges. *Supportive Care in Cancer*, *21*, 431-437. https://doi.org/1 10.1007/s00520-012-1532-6

Mosher, C. E., Adams, R. N., Helft, P. R., O'Neil, B. H., Shahda, S., Rattray, N. A., Champion, V. L. (2016). Family caregiving challenges in advanced colorectal cancer: patient and caregiver perspectives. *Supportive care in cancer*, *24*, 2017-2024. https://doi.org/10.1007/s00520-015-2995-z

Nissen, K. G., Trevino, K., Lange, T., Prigerson, H. G. (2016). Family relationships and psychosocial dysfunction among family caregivers of patients with advanced cancer. *Journal of pain and symptom management*, *52*(6), 841-849. https://doi.org/10.1016/j.jpainsymman.2016.07.006

Northouse, L. (1989). A longitudinal study of the adjustment of patients and husbands to breast cancer. *Oncology Nursing Forum*, *16*(4), 511-516.

Olson, D. H., Gorall, D. M. (2006). *Faces IV and the Circumplex model*. Life Innovations. Olson, D. H. (2011). FACES IV and the Circumplex Model: Validation study. *Journal of Marital and Family Therapy, 37*(1), 64–80. https://doi.org/10.1111/j.1752-0606.2009.00175.x

Otto, A. K., Ketcher, D., Heyman, R. E., Vadaparampil, S. T., Ellington, L., Reblin, M. (2021). Communication between advanced cancer patients and their family caregivers: relationship with caregiver burden and preparedness for caregiving. *Health communication*, *36*(6), 714-721. https://doi.org/10.1080/10410236.2020.1712039

Park, Y. Y., Jeong, Y. J., Lee, J., Moon, N., Bang, I., Kim, H., Yun, K.-s., Kim, Y.-I., Jeon, T. H. (2018). The influence of family adaptability and cohesion on anxiety and depression of terminally ill cancer patients. *Supportive Care in Cancer*, *26*, 313-321. https://doi.org/10.1007/s00520-017-3912-4

Parker, S. M., Clayton, J. M., Hancock, K., Walder, S., Butow, P. N., Carrick, S., Currow, D., Ghersi, D., Glare, P., Hagerty, R., Tattersall, , M. H. N. (2007). A systematic review of prognostic/end-of-life communication with adults in the advanced stages of a life-limiting illness: patient/caregiver preferences for the content, style, and timing of information. *Journal of pain and symptom management*, *34*(1), 81-93. https://doi.org/10.1016/j.jpainsymman.2006.09.035

Phillips-Salimi, C. R., Robb, S. L., Monahan, P. O., Dossey, A., Haase, J. E. (2014). Perceptions of communication, family adaptability and cohesion: a comparison of adolescents newly diagnosed with cancer and their parents. *International journal of adolescent medicine and health*, *26*(1), 19-26. https://doi.org/10.1515/ijamh-2012-0105

Rait, D. S., Ostroff, J. S., Smith, K., Cella, D. F., Tan, C., Lesko, L. M. (1992). Lives in a balance: Perceived family functioning and the psychosocial adjustment of adolescent cancer survivors. *Family process*, *31*(4), 383-397. https://doi.org/10.1111/j.1545-5300.1992.00383.x

Rodenbach, R. A., Norton, S. A., Wittink, M. N., Mohile, S., Prigerson, H. G., Duberstein, P. R., Epstein, R. M. (2019). When chemotherapy fails: emotionally charged experiences faced by family caregivers of patients with advanced cancer. *Patient education and counseling*, *102*(5), 909-915. https://doi.org/10.1016/j.pec.2018.12.014

Shin, J. Y., Steger, M. F., Shin, D. W., Kim, S. Y., Yang, H. K., Cho, J., Jeong, A., Park., K., Kweon, S. S., Park, J. H. (2019). Patient-family communication mediates the relation between family hardiness and caregiver positivity: Exploring the moderating role of caregiver depression and anxiety. *Journal of psychosocial oncology*, *37*(5), 557-572. https://doi.org/10.1080/07347332.2019.1566808

Shield, T., Bayliss, K., Hodkinson, A., Panagioti, M., Wearden, A., Flynn, J., Rowland, Ch., Bee, P., Farquhar, M., Harris, D., Grande, G. E. (2023). What factors are associated with informal carers' psychological morbidity during end-of-life home care? A systematic review and thematic synthesis of observational quantitative studies. *Health Services and Delivery Research*. https://doi.org/10.3310/HTJY8442

Stamataki, Z., Ellis, J. E., Costello, J., Fielding, J., Burns, M., Molassiotis, A. (2014). Chronicles of informal caregiving in cancer: using 'The Cancer Family Caregiving Experience'model as an explanatory framework. *Supportive care in cancer*, *22*, 435-444. https://doi.org/10.1007/s00520-013-1994-1

Svetina, M., Nastran, K. (2012). Family relationships and post-traumatic growth in breast cancer patients. *Psychiatria Danubina*, *24*(3.), 298-306.

Tan, J. Y., Molassiotis, A., Lloyd-Williams, M., Yorke, J. (2018). Burden, emotional distress and quality of life among informal caregivers of lung cancer patients: An exploratory study. *European journal of cancer care*, *27*(1), e12691. https://doi.org/10.1111/ecc.12691

Taylor, J., Fradgley, E., Clinton-McHarg, T., Byrnes, E., Paul, C. (2021). What are the sources of distress in a range of cancer caregivers? A qualitative study. *Supportive Care in Cancer*, *29*, 2443-2453. https://doi.org/10.1007/s00520-020-05742-0

Thana, K., Lehto, R., Sikorskii, A., Wyatt, G. (2021). Informal caregiver burden for solid tumour cancer patients: a review and future directions. *Psychology & Health*, *36*(12), 1514-1535. https://doi.org/10.1080/08870446.2020.1867136

Thomson, M. D., Genderson, M. W., Siminoff, L. A. (2022). Understanding cancer caregiver burden over time: Dyadic assessments of family cohesion, conflict and communication. *Patient Education and Counseling*, *105*(6), 1545-1551. https://doi.org/10.1016/j.pec.2021.10.014

Thomson, M. D., Wilson-Genderson, M., Siminoff, L. A. (2023). Cancer patient and caregiver communication about economic concerns and the effect on patient and caregiver partners' perceptions of family functioning. *Journal of Cancer Survivorship*, 1-9. https://doi.org/10.1007/s11764-023-01341-0

van Oosterhout, S. P., Ermers, D. J., Ploos van Amstel, F. K., van Herpen, C. M., Schoon, Y., Perry, M., van Geel, M., Kuip, E., J., M., Engels, Y. (2021). Experiences of bereaved family caregivers with shared decision making in palliative cancer treatment: a qualitative interview study. *BMC palliative care*, *20*, 1-10. https://doi.org/10.1186/s12904-021-00833-z

Van Schoors, M., Caes, L., Knoble, N. B., Goubert, L., Verhofstadt, L. L., Alderfer, M. A. (2017). Systematic review: Associations between family functioning and child adjustment after pediatric cancer diagnosis: A meta-analysis. *Journal of pediatric psychology*, *42*(1), 6-18. https://doi.org/: 10.1093/jpepsy/jsw070

Vrontaras, N. (2018). Cancer Patients' Views on the Family Changes and the Family Social Support. *Journal of European Psychology Students*, *9*(1), 16-27. https://doi.org/10.5334/jeps.403

Watson, D., Clark, L., Tellegen, A. (1988). Development and validation of brief measures of positive and negative affect: The PANAS scale. Journal of Personality and Social Psychology, 54, 1063- 1070. https://doi.org/10.1037/0022-3514.54.6.1063

World Health Organization. (2007). *Palliative care*. World Health Organization. Zhang, A. Y., Siminoff, L. A. (2003). Silence and cancer: why do families and patients fail to communicate?. *Health communication*, *15*(4), 415-429. https://doi.org/10.1207/S15327027HC1504_03

Zhou, Y., Hu, D., Zhang, K., Mao, J., Teng, F., Yu, T., Xu, K., Tan, R., Ding, X., Liu, Y. (2020). The mechanism of family adaptability and cohesion in suicidal ideation among Chinese cancer patients. *Journal of psychosocial oncology*, *38*(5), 612-626. https://doi.org/10.1080/07347332.2020.1757799