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Emotions Among Informal Caregivers for Home-Based Palliative Cancer Patients: the Role of Caregiving Duration and Informal Caregiver Health Perception

Abstract: The role of home-based palliative care is becoming increasingly relevant as a consequence of demographic changes and medical developments. Informal caregivers serve as singular members of the interdisciplinary team within such a caregiving system. Studies have systematically shown that the duration of care and the physical health of informal caregivers are related to the emotions (including stress) they experience. To date, however, there have been no such studies with regard to informal caregivers of oncology patients receiving home-based palliative care (IC-HPs), who appear to be a distinctive group due to the specific nature of such care. Therefore, the aim of this study was to fill this gap. The study involved 150 informal caregivers of patients receiving palliative care at home, including 44 men and 106 women aged between 22 and 77 years. Study participants declared the daily and overall time spent on caregiving and evaluated their physical health by answering demographic questions. Thereafter, the study verified the intensity of their positive and negative emotions (using the Positive and Negative Affect Schedule (SUPIN)) and stress (using the Perceived Stress Scale (PSS-10)). The study established that daily caregiving duration was a crucial predictor of the caregivers' negative emotions, including stress. These findings help to improve formal and informal care for this population of informal caregivers.

Keywords: *home-based palliative care, informal caregiver, caregiving duration, health condition, emotions, stress*

Home-based palliative care is playing an increasingly important role in today's world. It provides emotional and psychosocial support for the patients and their families (Effendy et al., 2022). Factors responsible for the growing demand for palliative care include the aging population (Caplan, 2024; Hu, 2020; Klostermann, 2023) and an increased number of people with chronic diseases (Maresova et al., 2019; Shelton et al., 2024; Xie et al., 2020; Wang et al., 2020; Young et al., 2009). Factors such as increased public awareness of the quality of life in the last stages of one's life (McCaffrey et al., 2016), economic aspects of medical care (Smith et al., 2014), and the preference of patients and their families for caregiving at home (Cai et al., 2021; Nysæter et al., 2022) emphasize the importance of home-based palliative care. A home-based care system is becoming an attractive alternative to traditional, institutional forms of care. Therefore, a home-based care system is a key element of healthcare. In this paper, the term Informal Caregivers of Oncology Patients Receiving Home-Based Palliative Care will be abbreviated as IC-HPs for conciseness. This abbreviation will be used throughout to refer to individuals providing unpaid, non-professional care to oncology patients within the context of home-based palliative care. Informal caregivers play a crucial role in home-based palliative care (Adejoh et al., 2021), and the role they play affects their functioning (Cherak et al., 2021; Tanco et al., 2021) and mental health (Fleitas Alfonzo et al., 2022). IC-HPs experience both positive and negative feelings. Research indicates that caregivers frequently encounter negative

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emotions, such as sadness, guilt, frustration, feelings of exhaustion, frustration, panic, fear associated with the death of their sick relatives and friends, fear of loss, and remorse (Lee et al., 2014; Leow & Chan, 2017; Monemian et al., 2024). IC-HPs often describe these emotions as challenging rather than merely negative, with ambivalence arising from the tension between the desire to extend their loved ones' lives and the wish to alleviate their suffering (Lee et al., 2014). Cultural expectations around caregiving further shape their emotional experiences, with a noted obligation to suppress these emotions and seek professional support when necessary. However, caregiving can also elicit positive emotions, including feelings of helpfulness, personal growth, self-satisfaction, and reward (Henriksson et al., 2015; Lee et al., 2014).

IC-HPs underscore their need for emotional support (Harding et al., 2012). Although there is growing recognition of the need for mental health improvement among IC-HPs (Ito & Tadaka, 2022; von Heymann et al., 2023), designing suitable multidimensional therapeutic interventions requires an understanding of the correlates of their mental state, including their emotional state. Washington et al. (2015) state that although informal caregivers of oncology patients and non-oncology patients share certain characteristics, fulfilling the role of an informal caregiver in the context of oncology hospice care is, in some ways, unique. The researchers note that this care is shorter in terms of the overall time spent on caregiving but is more intensive. These informal caregivers spend more hours per day providing care than others. This may be the result of the specific nature of the advanced stage of the disease and its rapid progression. Furthermore, the mental state of informal caregivers may vary depending on the condition of those in their care (Barnhart et al., 2020). In this context, it seems reasonable to pay attention to the population of IC-HPs. Moreover, Xue et al. (2024) highlight that the country-specific context plays a vital role in research on the dependency between the role of an informal caregiver and various indicators of the caregivers' functioning. The reason may be the specific character of providing support services within the framework of home-based palliative care in different countries. Consequently, the decision was made to conduct this study within the IC-HPs population in Poland. In previous international studies of the mental health of informal caregivers, researchers often pointed to the duration of informal caregiving and the health of the informal caregivers as correlates.

DURATION OF INFORMAL CAREGIVING

One of the factors related to the mental health of informal caregivers and, above all, to the emotions they experience, is caregiving duration. In this context, researchers analyze either the overall time devoted to this role or the number of hours per day, week, or month that caregivers spend on providing care (Lindt et al., 2020).

Lindt et al. (2020) reviewed the scientific literature to establish the determinants of the caregivers' burden in western countries. Their study demonstrates that one of the most important factors is the overall caregiving duration. Other research found that, among caregivers of elderly people (Sugihara et al., 1998) and individuals with Alzheimer's disease (Conde-Sala et al., 2010), the caregiving burden progressively intensifies over time following the onset of symptoms. Furthermore, research indicates that prolonged engagement in informal caregiving over an extended period can lead to enduring negative consequences for mental health (Stöckel & Bom, 2022). Badaru et al. (2019) arrive at contrasting results. The researchers do not confirm a correlation between the overall caregiving duration and the caregivers' burden or the quality of life. Lacey et al. (2019), on the other hand, establish that women who fulfill an informal caregiver role for more than three years or on a periodical basis show higher levels of stress compared to women who do not play such a role. The study does not confirm such a dependency in men. Although existing research indicates a correlation between the duration of caregiving and the intensity of emotions, this relationship may not be as evident when applied to IC-HPs. In this specific context, the proximity of death may be a critical factor (Janze & Henriksson, 2014). While prior studies suggest that longer caregiving periods are generally associated with heightened emotional distress, it is also plausible that increased time spent with a terminally ill loved one may lead to a sense of emotional fulfillment or acceptance, as caregivers are acutely aware of the limited time remaining. This awareness could potentially mitigate the negative emotional impact commonly linked to prolonged caregiving, suggesting that the relationship between caregiving duration and emotional intensity may be more complex than initially assumed. Conversely, the anticipation of a loved one's impending death, coupled with their ongoing suffering, may exacerbate the emotional distress experienced by IC-HPs. As previously demonstrated, IC-HPs represent a distinct cohort of informal caregivers who experience a diverse array of emotional responses. Consequently, examining the dynamics of this relationship may significantly enhance our understanding of the correlates associated with their emotional experiences. Therefore, this study poses the following hypothesis:

H1 Overall caregiving duration predicts a) positive emotions, b) negative emotions, c) stress felt by informal caregivers of home-based palliative care patients.

Some researchers focus on daily caregiving duration. The number of hours per day dedicated to caregiving is related to caregiver strain, which may manifest itself as emotional distress (Liu et al., 2020). Research demonstrates such a dependency in regard to informal caregivers of people with dementia (Lethin et al., 2020), stroke (Badaru et al., 2019), older people (de Almeida Mello et al., 2017; Oh et al., 2024), as well as people with bipolar disorder and schizophrenia (Blanthorn-Hazell et al., 2018). Additionally, the weekly duration of caregiving hours is significantly correlated with the experience of role overload (Yates i in., 1999). Cannuscio et al. (2002) reported that women who indicated providing care for a disabled or ill spouse for 36 or more hours per week were nearly six

times more likely to exhibit symptoms of depression or anxiety during the follow-up period compared to their non-caregiver counterparts. In addition, Stöckel and Bom (2022) conclude from their research that providing more than 20 hours of caregiving per week results in detrimental effects on the mental health of informal caregivers. The study conducted by Akpan-Idiok and Anarado (2014) establishes a similar correlation by analyzing monthly caregiving duration. In contrast, Zhang and Bennett (2024) focus their research on the relationship between the number of hours British informal caregivers spend every week on caregiving and their psychological well-being, which includes the absence of emotional distress. The researchers found that care provided for more than five hours a week is associated with lower psychological well-being, regardless of whether the caregivers live with those in their care. The number of caregiving hours lower than five is associated with higher levels of well-being but only in relation to caregivers who do not live with the person in their care. Badaru et al. (2019) establish that Nigerian people who care for their relatives who have suffered a stroke for more than twelve hours per day have a worse quality of life than those who also act as caregivers but devote fewer hours per day to caregiving. Kumagai (2017) demonstrates that spending a very high number of hours on caregiving per week is associated with poorer mental health in non-working Japanese caregivers, with the working caregivers failing to demonstrate such a dependency. However, the relationship described is particularly intricate in the context of IC-HPs. On one hand, evidence from previous studies suggests that an increased number of caregiving hours is associated with heightened negative emotional states. Among IC-HPs, this effect may be further amplified by the anticipation of the patient's imminent and inevitable death (Janze & Henriksson, 2014). On the other hand, IC-HPs may deliberately maximize the time spent with the patient, recognizing the finite nature of these moments, which could foster a sense of emotional fulfillment and positively influence their overall well-being despite the challenges. Given the distinctive emotional experiences reported by IC-HPs, as outlined in earlier studies, investigating the relationship between these emotions and relevant variables could yield critical contributions to our understanding of the psycho-social correlates of their caregiving roles. Thus, this study puts forward the following hypothesis:

H2 Daily caregiving duration predicts a) positive emotions, b) negative emotions, c) stress felt by informal caregivers of home-based palliative care patients.

HEALTH CONDITION

Informal caregivers are more likely to experience a decline in physical health compared to non-caregivers (Vitaliano et al., 2003; Riemsma et al., 1999; Schulz et al., 1995). This deterioration is closely linked to the stressors they encounter in their caregiving roles (LeBlanc et al., 1997). Furthermore, poor physical health has been found to significantly affect informal caregivers of palliative care patients (Kenny et al., 2010). However, the relationship between fulfilling the role of a caregiver and physical health is not clear. The study conducted by Zwara et al. (2018) found no direct relationship between assisting the patient with household chores as well as providing care or nursing-related activities for the patient and the physical health of the caregivers (prevalent diseases and lung capacity). Conversely, researchers established such a dependency in regard to the relationship between different forms of informal caregiving and the subjectively perceived health condition. Pinquart and Sörensen (2007) review the scientific literature in relation to the physical health of informal caregivers of older people. They found that several factors impact the physical health of caregivers, namely the intensity of symptoms experienced by those in their care, the deterioration of their cognitive function, cohabitation, caring for a person other than a spouse, depression, older age, lower socioeconomic status, and lack of informal support. Scholars emphasize that these correlations are stronger for depression than for other stressors. This means that the physical health of informal caregivers is closely connected to their mental well-being. Teixeira et al. (2019) indicate that elevated stress levels in informal caregivers can cause deterioration of their physical health and point to the possibility of them developing diseases such as cancer or cardiovascular disease. The patients' assessment of their health as poor is, in turn, a significant predictor of their level of burden (Rodríguez-González et al., 2021) and is, therefore, related to their emotional state. Nonetheless, the dynamics of this relationship are particularly nuanced among IC-HPs. On one hand, the perception of symptoms may lead to the belief that they are indicative of a developing illness, mirroring the advanced-stage disease currently being observed in a close relative. This association can result in heightened stress levels. On the other hand, perceiving one's own health as good may evoke feelings of guilt in relation to a loved one who is enduring significant suffering and nearing the end of life. IC-HPs, as previously demonstrated, are a specific group of informal caregivers who experience a wide array of emotional responses. Examining this relationship, therefore, holds the potential to provide profound insights into the psychological determinants that underlie their caregiving dynamics. Thus, this study puts forward the following hypothesis:

H3 The perceived physical health condition of informal caregivers of patients receiving palliative care at home predicts a) positive emotions, b) negative emotions, c) stress.

METHOD

Participants

The study is part of a larger research project that aims at the cross-cultural validation of the questionnaire used to assess the functioning of informal caregivers. The study comprised 150 informal caregivers of patients receiving palliative care at home (for at least two weeks), including 44 men and 106 women. Study participants ranged in age

from 22 to 77 years *(M* = 48.7; *SD* = 14.6). Study participants provided care for their mother (34 people), father (31 people), husband (27 people), wife (17 people), grandmother (9 people), grandfather (7 people), son (7 people), daughter (7 people), mother-in-law (4 people), cousin (3 people), sister (3 people), and brother (1 person). As many as 101 informal caregivers stated that they lived with the person in their care. As many as 146 respondents declared their voluntary assumption of the role of an informal caregiver. The researchers conducted the recruitment of informal caregivers for the project with the assistance of psychologists working in home hospices in different cities (for example, Kraków, Siedlce, Katowice, Świdnica, or Pleszew). Participation in the study was voluntary and anonymous. Each informal caregiver received a bookshop voucher worth PLN 25 at the end of the study.

The people in the care of informal caregivers included 68 men and 82 women, who were between 5 and 96 years old (*M* = 64.5; *SD* = 18.3). All individuals were under the care of a home hospice because of the advanced stages of cancer.

Tools

Skala Uczuć Pozytywnych i Negatywnych SUPIN: Polish adaptation (Brzozowski, 2010) of the Positive and Negative Affect Schedule (PANAS) (Watson et al., 1988). This tool assesses 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 (for example, nervous), which study participants rate on a scale from 1 (very slightly or not at all) to 5 (extremely). The participants can obtain between 10 and 50 points on each scale. The higher the score obtained on each scale, the greater the intensity of the emotion in question. Depending on the version and type of sample, Cronbach's alpha reliability indices range from .73 to .95 in validation studies. In this study, the indices were .93 for the Negative Affect Scale and .90 for the Positive Affect Scale, respectively.

Skala Odczuwanego Stresu PSS-10: Polish adaptation (Juczyński & Ogińska-Bulik, 2009) of the Perceived Stress Scale (PSS) (Cohen et al., 1983). This tool measures the intensity of stress. The study consists of 10 questions (Such as "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 follows 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.

Own demographics: This tool enabled the analysis of the following variables: caregiving role duration: number of months spent providing care as declared by the subject; daily caregiving duration: number of hours spent per day on providing care as declared by the subject; physical health: physical health condition as assessed by the subject on a scale from 1 (very poor) to 5 (very good).

Procedure

In the first part of the project, study participants signed a consent form to participate in the study and a GDPR consent form. They then completed a form with questions relating to their personal data and the form of care provided. Finally, study participants completed a number of questionnaires, including the Positive and Negative Affect Schedule (SUPIN) and the Perceived Stress Scale (PSS-10). At the end of the study, each informal caregiver received an Empik store voucher and signed a document acknowledging its receipt. The project took place between January and October 2023.

RESULTS

The researchers used the IBM SPSS Statistics (version 29) software to verify the research hypotheses by means of statistical analyses. With the aid of the software, the researchers performed an analysis of linear regression. This article assumed the significance level as $\alpha = 05$.

First, the researchers examined the overall and daily duration of providing informal care for palliative oncology patients at home and the perceived health condition of informal caregivers to predict the intensity of positive and negative emotions, including stress. Table 1 presents the descriptive statistics of the measured variables.

The researchers performed three linear regression analyses, and Table 2 summarizes the results.

The results of the analysis of variance showed that models predicting the intensity of negative emotions and the level of perceived stress were a good fit for the data. As the study obtained a statistically insignificant result for the

Table 1. Descriptive statistics of measured variables

Variable	*M*	*Standard Deviation*	*Skewness*	*Kurtosis*	*Min.*	*Max.*	*Scale range*
Positive emotions	31.81	8.61	-.51	.19	0	47	10-50
Negative emotions	23.02	9.82	.47	-.55	0	49	10-50
Stress	21.08	7.39	-.14	-.13	0	37	0-40
Overall caregiving duration	32.96	39.73	3.47	17.1	1	300	-
Daily caregiving duration	9.13	7.30	1.13	0.01	1	24	-
Perceived physical health condition	3.95	0.80	-.39	-.33	2	5	1-5

Table 2. Results of linear regression analysis predicting positive and negative emotions, including stress, in the caregiver based on caregiving duration and the perceived physical health condition of the informal caregiver

Response variable		*B*	*SE*	*beta*	*t*	*p*
Positive emotions	***F*(3;144) = 0.21; *p* = 0.890; *R²adj.* <0.001**					
	Overall caregiving duration	.01	.02	.03	.41	.680
	Daily caregiving duration	-.01	.10	<,01	-.09	.931
	Perceived physical health condition	.61	.90	.06	.68	.496
Negative emotions	***F*(3;144) = 5.57; *p* = 0.001; *R²adj.* = 0,085**					
	Overall caregiving duration	-.03	.02	-.14	-1.76	.080
	Daily caregiving duration	.34	.11	.25	3.13	**0.002**
	Perceived physical health condition	1.35	.97	.11	1.39	.166
Level of perceived stress	***F*(3;144) = 3.28; *p* = 0.023; *R²adj.* = 0,045**					
	Overall caregiving duration	-.03	.01	-.14	-1.71	.090
	Daily caregiving duration	.18	.08	.18	2.17	**.031**
	Perceived physical health condition	.77	.74	.08	1.04	.301

Note. B – non-standardized regression factor; *SE* – standard error; *Beta* – standardized regression factor; *t* – Student's t-test result; *F* – analysis of variance result; *R²adj.* – adjusted R-square.

positive emotions indicator, the variables entered into the model failed to significantly predict the intensity of this variable.

Both in the case of the negative emotions indicator and the indicator of the perceived stress intensity, the only significant predictor was daily caregiving duration. The results of the study partially confirmed hypothesis 2. In both cases, the Beta value was positive, indicating an increase in negative emotions, including stress levels alongside an increase in daily caregiving duration. At the same time, in both cases, the adjusted R2 value was relatively small – 8.5% for the model predicting negative emotions and 4.5% for the model predicting levels of perceived stress. The study did not confirm hypotheses 1 and 3.

DISCUSSION OF THE RESULTS

This study intended to investigate whether informal caregiving duration (general and daily) and the perceived physical health condition of informal caregivers are predictors of their emotions. To date, studies showing such differences and correlations involved informal caregivers mainly from western and southern countries, as well as informal caregivers of patients other than oncology patients receiving home-based palliative care. Meanwhile, IC-HPs require additional attention due to the nature of the care they provide (Barnhart et al., 2020; Washington et al., 2015; Xue et al., 2024).

The researchers assessed whether the overall caregiving duration (H1) and daily caregiving duration (H2) predict a) positive emotions, b) negative emotions, c) stress felt by IC-HPs. The study established that daily caregiving duration was a crucial predictor of the caregivers' negative emotions, including stress. These findings are in line with those obtained in previous studies on caregivers of different patient groups (Badaru et al., 2019; Blanthorn-Hazell et al., 2018; de Almeida Mello et al., 2017; Lethin et al., 2020). The results of the study are relevant from the perspective of the mental well-being of informal caregivers. The more hours per day informal caregivers devote to home-based palliative care, the more negative emotions, including stress they experience. Devoting a lot of time to a dying relative or close friend can result in a heightened awareness of their serious health condition. Such a reflection can be conducive to emotional discomfort. Furthermore, the more time an individual spends on providing care, the less time they have to take care of their own needs (e.g. rest). Although the overall duration of providing palliative care at home is often relatively short due to the advanced stage of the disease, and sometimes informal caregivers fail to report not having the capacity to care for themselves (Paul & Fernandes, 2020), they may experience problems in reserving time for themselves (Harding et al., 2012). As a result, they may experience negative emotions, including stress. This study established that, on average, study participants had already spent more than two and a half years in informal home-based hospice care, so they had been fulfilling the role of an informal caregiver for a relatively long time. Taking these correlations into consideration, it would be prudent

to raise awareness among informal caregivers of the possibility of using respite care. Although informal caregivers are in need of this form of support, they do not ask for it (Van Exel et al., 2008).

In the conclusion of the study, the researchers assessed if the perceived physical health condition of IC-HPs predicts a) positive emotions, b) negative emotions, c) stress (H3). The results of the study did not confirm this hypothesis. However, certain researchers indicated such a dependency (Pinquart & Sörensen, 2007; Rodríguez-González et al., 2021; Zwara et al., 2018). There is a likelihood that IC-HPs make an assessment of their own health condition based on the condition of their dying relative or close friend, which they observe on a daily basis. As a result, their assessments may not reflect the reality and may be exaggerated. Another possibility is that informal caregivers looking after their relatives at home divert all their attention to them and fail to focus on their own health. Although fulfilling the role of an informal caregiver does not equal a deterioration of physical health (Longobardo et al., 2023), there is a likelihood that informal caregivers do not notice somatic symptoms in themselves because they do not focus on themselves. Their emotions have ties to factors quite different from their own health, such as the patient's poor health condition (Harding et al., 2003) or difficulties in sourcing medical equipment for the patient (Ventura et al., 2014).

LIMITATIONS

The study had its limitations. First, there was a large disparity in the numbers of female and male informal caregivers. The vast majority of study participants were women. While a similar pattern was also present in other studies of informal caregivers (for example, Brazil et al., 2009; Ochoa et al., 2019), caution is necessary when generalizing the results obtained to the entire population of informal caregivers. Second, the wide age range of participants (22 to 77 years) may complicate the interpretation of the correlations between variables. This broad age spectrum introduces the possibility of confounding factors, as age could influence participants' needs, life goals, and emotional experiences, potentially affecting the observed relationships between the variables under study. Third, study participants self-assessed their health condition. Although they did so by means of a specific scale, they were free to adopt different reference points, for example, the advanced illness of a relative. A more precise approach to measurement would involve inquiring about specific diseases and medical conditions. Furth, respondents may have interpreted daily caregiving duration in different ways, as indicated by the hours they declared. Some respondents specified 24 hours, meaning that they also included night hours in caregiving duration. Such indications are reasonable, as some patients receiving home-based palliative care also require assistance during the night (Kenny et al., 2010), and the guidelines did not specify whether night-time assistance should be taken into account. Hence, not all informal carers took it into consideration. Therefore, the estimates of daily caregiving duration may be excessively low. Perhaps it would be more accurate to consider the number of hours spent on providing care within 24 hours. Fifth, the study did not analyze whether and in what form informal caregivers received support themselves, for example, from other family members or professionals. Such support could affect both their emotions and caregiving duration (Harding et al., 2012; Rao et al., 2021).

CONCLUSIONS AND FURTHER DIRECTIONS FOR RESEARCH

This study demonstrated that the daily duration of providing care for palliative oncology patients at home (but not the overall duration of care) is a crucial predictor of the intensity of negative emotions, including stress. To the best of my knowledge, this is the first study to address such aspects in relation to this particular population of informal caregivers. This study offers valuable insights for both the remaining family members and the interdisciplinary home-based palliative care team, which could aid in the development of appropriate support strategies. The findings indicate that caregiver well-being is positively associated with the opportunity to rest during the day, even though it shows no correlation with the total duration of caregiving. Additionally, the study established that the overall duration of care and the physical health of informal caregivers were not significant predictors of the intensity of positive and negative emotions, including stress. In the future studies, the introduction of an additional, more objective measure of the physical health of informal caregivers and a more precise measurement of the time spent on the provision of informal care within 24 hours may prove valuable.

COMPLIANCE WITH ETHICAL STANDARDS

The Ethics Committee of the Institute of Psychology at Kraków's University of the National Education Commission approved the study. The study was performed in accordance with the ethical standards as set forth in the 1964 Declaration of Helsinki and its later amendments.

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