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ORIGINAL PAPER

I'll do everything for him / her: the experiences of family caregivers caring for a dying patient at home (a phenomenological qualitative approach)

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Abstract

Aim: The aim was to understand the lived experiences of family caregivers caring for a dying patient at home. *Design:* A qualitative phenomenological approach was used. *Methods:* Data were collected between September and December 2018. Data collection was took the form of in-depth interviews with family caregivers (n = 4), followed by the use of interpretative phenomenological analysis (IPA). *Results:* Five main themes were identified in terms of which family caregivers described their experience: the Role of caregiver; I'll do everything for him / her; Support; "Time out" after death; and Benefits of care. The family caregivers had to establish their new caregiver roles, often they were the mainstay of the whole family. In the various areas of care they did everything for the dying person. They experienced pain, mental and physical burdens, and doubts, and spirituality was vital to them. It was important to experience support from different sources. After this experience, the caregivers needed time to release emotions after the death. Overall, the caregivers came to regard this experience as beneficial: revealing other priorities, increasing time spent with family, clarifying relationships, and changing attitudes and values. *Conclusion:* The study offers a unique insight into family caregivers' experiences in the Czech Republic. In confirmation of previous results, experiences are generally similar for all caregivers and point to a need for significant improvement in the quality of support and assistance from health professionals and support from family members, particularly in the areas of practical demonstration of care, the expression of condolences, provision of pain medication, handling of formalities related to the death of a loved one (e.g., when arranging the death certificate and widow's pension), and the sharing of emotions as they occur.

Keywords: dying, experience, family caregiver, home care, interpretative-phenomenological analysis.

Introduction

The population is aging in most countries of the world (Turner et al., 2016). More and more people are choosing to stay and receive care in their home environment (Social Care Institute for Excellence, 2013). Although the number of deaths in hospital facilities remains high, the number of people dying at home is increasing (Higginson et al., 2013; Morris et al., 2015). In 2020, almost 2/3 of all deaths occurred in a hospital or medical institution, and another 10.7% of deaths occurred in a social care facility. More than a fifth of people in the Czech Republic died at home (Institute of Health Information and Statistics of the Czech Republic, 2020).

Home care is also one of the key aspects of palliative care. The home is an important and often preferred setting for palliative care. Based on the review, six; essential elements for high-quality palliative homecare were determined: Integrated teamwork; Management of pain and physical symptoms; Holistic care; Caring, Compassionate and skilled providers; Timely and responsive care; and Patient and family preparedness (Seow & Bainbridge, 2018). Palliative care is active quality-of-life care for the terminally ill and their relatives (Sláma, 2012). It's goal is to improve the quality of life of patients and families through the prevention and alleviation of suffering. Patients can often choose to receive palliative care at home. Palliative care in the home environment is the provision of specialized palliative care in the patient's home, most often provided by nurses and / or doctors with or without a connection to a hospital or hospice (Nordly et al., 2016).

In the last phase of a life-limiting disease, patients are often cared for by so-called informal caregivers. An informal caregiver is any individual, such as a family member or friend, who provides regular and continuous help to another person without receiving payment for what they do. It has been

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reported that such informal caregivers are increasingly providing care to those in need of palliative care. However, the majority of informal caregivers do not have prior knowledge related to the provision of care. Their role as informal caregivers is very stressful for some, including the need to face the imminent death of the patient (Seal et al., 2015). On the other hand, due to their often-unique relationship with and valuable knowledge of the patient, family caregivers are essential in providing emotional support, communicating with professionals and services, alleviating pain and other symptoms, or performing practical tasks (Vermorgen et al., 2021). According to the World Health Organization (WHO) definition, the needs of family members should also be addressed within this care. There is discussion also of so-called significant others, i.e., those important to patients regardless of their relationship (Bužgová et al., 2013).

Family caregivers play a key role in dying at home. The likelihood that a patient will die at home depends mainly on their own efforts and the availability of care (Gomes & Higginson, 2006). Even when patients have access to home care, their chances of dying at home are drastically reduced if family members are unable or unwilling to provide the care they need (Grande & Ewing, 2008). Thus, family caregivers form the basis of home care (Stajduhar et al., 2010). However, if the patient wishes to stay and die at home, as most initially prefer (Gomes et al., 2013), the roles and responsibilities of their families and friends intensify (Morris et al., 2015; Rowland et al., 2017) and care can become burdensome. Family caregivers are estimated to be responsible for 75–90% of home care (Robinson et al., 2017). During the entire period of care, family caregivers need support, especially from health professionals. Caregivers should be not left alone since they are the greatest support of the patients. Based on current research, family caregivers mainly need the following forms of support from health professionals: practical demonstration of care, good pain and symptom management, access to equipment in the home to address physical needs, the opportunity to share emotions, and access to a member of the care team round the clock (Bainbridge et al., 2017; Holland et al., 2015; Seow & Bainbridge, 2018).

Family caregivers face many challenges and problems. They experience a significant change in lifestyle (Choi & Seo, 2019; Martín et al., 2016; Morris et al., 2015), a decrease in physical and mental health (Funk et al., 2010; Linderholm & Friedrichsen, 2010; Stajduhar et al., 2010), financial burdens (Choi & Seo, 2019; Morris et al., 2015), confusion and anxiety (Bee et al., 2009; Milberg & Strang, 2007), and feelings of helplessness (Linderholm & Friedrichsen, 2010) and fear (Phillips & Reed, 2009). Caring for a dying family member is associated with exhaustion, fatigue, insomnia, weight loss, depression, and burnout (Bijnsdorp et al., 2022; Choi & Seo, 2019; Jo et al., 2007; Morris et al., 2015). Maintaining normality in social relationships can be a struggle, for example, when the caregiver's obligation to be at the patient's bedside runs up against feelings of social isolation (Morris et al., 2015; Van Roij et al., 2019). All these reasons have led to the care of family members being identified as an international research priority in end-of-life care (Hagen et al., 2006; Stajduhar et al., 2010). Therefore, many reviews have recently emerged focusing on the experiences of family caregivers with terminally ill patients. Many family caregivers have unmet needs, especially in certain areas: communication with healthcare professionals, spiritual needs, assistance with mobility and financial support, information about the progression of the disease, opportunities to rest (Ventura et al., 2014), and support that enables death in the home and transformation of social and emotional space of the home (Morris et al., 2015). Involvement in the dying process entails considerable physical and psychological strain, along with substantial limitations to the normal development of the caregiver's own life. In addition, the caregiver must establish a new relationship with the family member in accordance with the new ethos without the help of a formal structure providing the necessary support (Martín et al., 2016). Authors Funk et al. (2010), in their comprehensive review focusing on key findings and identifying gaps where additional research is needed, recommend that future research focus on the following topics: the bereavement experience, caregiver ambivalence, access to services, caregiver meaning-making, and relational and contextual influences on family caregiving at the end of life. All these results may help focus attention on the needs of family caregivers and develop the knowledge needed to meet current demands for end-of-life care in the home.

In the Czech Republic, organized palliative care is in its infancy, and as far as we know, there are no published qualitative studies on the experiences of informal family caregivers providing palliative care. Until now, research has focused on the needs of family members caring for a dying relative at home solely from a quantitative point of view, using the standardized questionnaires, the Family

Inventory Needs (FIN) and the Quality of Life in Life-threatening Illness-Family (QOLLTI-F) (Bužgová et al., 2013). However, there has been no comprehensive qualitative research study dealing with the experience of family members from a holistic point of view. Consequently, it is not known how informal family caregivers of dying patients cope when they need to provide palliative care and what kind of help they require from health professionals. A greater understanding of these experiences can help healthcare professionals provide better assistance to patients and their families.

Aim

The aim was to understand the lived experiences of family caregivers caring for a dying patient at home. The main research question identified was: how do family caregivers regard their experience of caring for a dying patient at home?

Methods

Design

A qualitative phenomenological approach was adopted. The research protocol was written according to Standards for Reporting Qualitative Research (SRQR) guidelines (O'Brien et al., 2014).

Sample

Snowball sampling was selected. To find and contact participants, researchers of the project made use of their personal connections.

Participants who met the following criteria were included in the research:

- a family or close caregiver who has cared for a dying person in the home environment;
- the death of the person cared for occurred a minimum of six months and maximum of two years before (a period selected after consultation with a psychologist who recommended this period as optimal for a conversation on the given topic);
- the caregiver was over 18 years of age;
- provision of signed informed consent to be included in the research.

The sample consisted of four family members (Table 1). Based on the current literature regarding the IPA method, four participants are deemed an adequate sample size for this method (Smith & Osborn, 2015).

Table 1 Characteristics of family caregivers

	A	**B**	**C**	**D**
Age	51	42	43	50
Relationship	daughter	granddaughter	daughter	daughter
Condition	Ca pancreatic	Ca colorectal	Ca ilea	Ca liver
Duration since death	2 years	2 years	2 years	1.5 years
Occupation	waitress	head nurse DsP	nurse ADP	saleswoman

ADP – Home Care Agency; Ca – cancer; DsP – Home for the elderly

The following are the brief biographies of the individual participants:

Participant A was 51 at the time of the interview and worked as a waitress. She cared for her dying father (79 years) intensively for about a month. The father was the head of the family, a recognized authority, with a strong sense of humor. Around the same time, her husband was diagnosed with serious heart disease and, shortly before, she had lost her unborn granddaughter (in the seventh month). Despite these tragic circumstances, when his condition suddenly worsened, she decided to go to a village 70 km away to take care of her dying father, who her mother (78 years) had been taking care of until then. Her husband and children (daughter and son) understood the situation. There was a strong Christian element in the family. For the last five days before the father's death, the extended family (his two daughters with their families, and grandchildren) gathered at the house. During the demanding care process, they took turns and supported each other.

Participant B was 42 when she began caring for her dying grandfather and worked as a senior nurse. She was divorced and raising a 15-year-old son. The grandfather (91 years) had had repeated strokes, but always tried to recover. Recently, he had been repeatedly hospitalized and his strength was waning. He was then diagnosed with colorectal cancer and his condition gradually worsened. Until then, his wife (86 years) had taken care of him with the help of the Home Care Agency. Participant B (granddaughter) visited the family regularly and lived in the same city. She had had a very close relationship with her grandfather since childhood. She was aware of his old age and terminal illness.

She regarded her grandfather's death as natural considering his old age. Participant C was 43 when she took care of her dying father and worked as a nurse at the Home Care Agency. The father (60 years) had been treated for two years for carcinoma of the ileum. Participant C was divorced and had a 12-year-old son. The father became very attached to his daughter when causal treatment was changed to palliative care and his health condition gradually worsened. The father had closed himself off from his wife and son and communicated only with the caring daughter. He refused to accept all care from his wife, which was very challenging. Although participant C occasionally cared for the dying in her work as a nurse, she was surprised by her own vulnerability and emotional lability during and after the care.

Participant D was 50 when caring for her dying mother (72 years) and worked as a salesclerk. The mother's condition suddenly worsened and, within six weeks of her liver cancer diagnosis, she died at home in the care of her daughter. The participant was married and had two children (12 years and 14 years) and lived in the same village. Her mother lived in a household with her invalid husband (75 years), so she cared for her mother alone. Her brother was not actively involved in the care. The initial uncertainty and vagueness of the diagnosis and the rapid deterioration of the mother's condition were difficult. She had support from her husband and daughters, who managed independently in the original household. With the death of the mother, relations in the family became very strained over the question of inheritance.

Data collection

Data collection was ensured using the methodology of phenomenological interviews. The first area of conversation concerned the story of the dying and caring. The task of the first phase of the interview was to extract as much information as possible in relation to death at home. The second phase of the interview was a detailed description of the experience of caring for the dying at home. Specific details of the experience were revealed. In the third phase, the caregivers' plans for the future and the role their experiences played were identified. The interviews lasted approximately 30–60 minutes and were recorded on two dictaphones. Two interviews were conducted by the first researcher and two by the second. During the interview, notes were taken in which other aspects of the situational context were captured, such as the place and atmosphere of the interview and non-verbal expressions of the participant. A sample of the questions used in the phenomenological interview is given in Table 2. Each audio recording, field note, and verbatim transcript of the interview was coded for reasons of anonymity. The increase in the trustworthiness and credibility of the research survey was ensured at this stage by the triangulation of data sources. Prior to the analysis itself, the audio recording was transcribed literally and transcription tags were added (Smith et al., 2022).

Table 2 Questions used during the interview

Questions
Tell me, what was it like when you learned that your loved one was sick?
Tell me about your experience with caring for your loved one?
Tell me about your experience of dying at home?
What was the best thing about being a caregiver for a person who was dying at home? Why?
What was the worst thing about being a caregiver for a person who was dying at home? Why?
What are your plans for the future? What role has this experience played in them?

Data analysis

In order to gain a unique insight into these experiences, analysis of the interviews was performed using interpretative phenomenological analysis (IPA). The aim of this analysis is to understand lived human experience. It helps us to examine in detail how a person shapes the meaning of his / her experience, and what importance a person attaches to it. For this reason, a large number of participants is not necessary. Attention is focused on gaining the unique perspective of the participant (Smith & Osborn, 2015). The use of the IPA method in this study was intended to achieve a comprehensive understanding of lived experiences which individuals tried to interpret and understand from their own point of view. IPA proceeds by the following steps:

Step 0: Reflection on the researcher's experience with the research topic.
Step 1: Reading and re-reading of the transcript.
Step 2: Initial remarks and comments.
Step 3: Development of emerging themes.
Step 4: Search for context across themes (Smith & Osborn, 2015).

After generating the initial codes, the analysis involved working systematically through the data set looking for repeated patterns. The codes were sorted into categories and sub-themes. Once the initial data was coded and collated, a long list of codes was produced representing the data set. A broader level of themes was established by sorting the different codes into potentially more meaningful themes (Fox, 2014). The specific illustration and descriptions of the themes were also important. A theme captures something important about the data in relation to the research question and represents a level of patterned meaning within the data set. During this process, sub-themes were also identified that emerged from the themes. Figure 1 shows how the authors worked from examples of quotations to subthemes and to main themes. The analysis itself was performed by two researchers independently of each other (triangulation of investigators). As part of the reflexivity and positionality of the research, both authors had personal experience of caring for a dying relative. One cared for her grandfather at home, while the other worked as a nurse in a palliative home care service. Both were simultaneously engaged in palliative care and academic activities.

Citation	Sub-theme	Theme
Thanks to this cousin here actually, she's our guardian angel, so she said get a reclining bed. That will be needed anyway, yes. So the brother actually got a reclining bed …	family support	suppport
I have a good doctor, so I agreed that the only solution for me at that moment was to go on sick leave and see what happens next.	professional support	suppport
The worst thing for me was that she actually died that night. I was sleeping and she woke me up. She didn't really talk the day before and woke me up as if she wanted a drink. So I said "mom, mom" and that was probably the last breaths (crying).	an intimate moment of death	benefits of care
In this situation, I didn't understand people (um) who (um) who, when someone close to him died, said that at least he was relieved. Hey, I didn't understand. But now I understand.	changing attitudes and values	benefits of care
... and that she was, of course she was sad, but she also had a good feeling in her, from the fact that the grandfather simply left in peace, in peace, that he stayed at home ...	an intimate moment of death	benefits of care
He basically said goodbye to her and, well. So it was like that, so from this point of view, even though it may sound strange, from this point of view, the experience of dying at home was simply good. And I think that even my aunt, who didn't take part in it at all, my mother 100%, so we know that one day grandma will get into this situation, so if it goes just a little bit, so I will want to do the same for grandma, that she I'll just let her go home.	changing attitudes and values	benefits of care
... I know that it helped her with the pain, but it didn't solve anything and the communication was lost with her, yeah. That it wasn't the same.	doubts	i'll do everything for him/her

Figure 1 Example of data analysis

Results

Finally, five main themes were identified in terms of which family caregivers described their experience: the Role of the caregiver; I'll do everything for him / her; Support; "Time out" after death; and Benefits of care (Table 3). Figure 2 shows a thematic map of family caregiver experiences, which represents a cyclical model.

The role of the caregiver

The role of the caregiver identifies, in particular, the position of the caregiver and the beginning of care for the dying loved one. For most it was a quick decision. According to the experience of the interviewees, *the setting of the role of the caregiver* was based on family relationships before the illness. In the case of a strong family bond, the decision was made to become a caregiver on the basis of emotional ties and the relationship to the dying person (e.g., child / daughter – parent). The motivation was the reciprocity of care for parents and the fulfillment of the patient's desire to die at home, among loved ones. Taking responsibility for care, *the caregiver "as mainstay"* deferred not only her own needs but also those of her family members. Most caregivers also tried to shield and support the rest of the family. One of the participants described her situation: *"So, at the time, I really said to myself that I had no choice but to endure it in some way. Hey, in front of children, one has to pretend that my father is okay, to maintain their morale somehow"* (Caregiver A).

Home caregivers not only played this role but also remained in the social roles they had occupied before then. The double role sub-theme describes the demanding fulfillment of multiple roles in caring for a dying loved one. In two cases (Caregivers B and C) they also held the position of general nurse. They were automatically expected by their family to be the leader of those involved in the care. There was also a conflict between the roles they played: daughter / granddaughter – father / grandfather vs. caring professional providing care even in intimate matters related to hygiene. As caring professionals, they were prevented from showing their family the sadness they felt as relatives: *"During that care, I had such a (pause) ... I may have it in me that I can seem to switch to 'pro mode', yeah. So, the moment I took care of my grandfather, of course, she was there, there was also the huge feeling I had for my grandfather, but as far as my own care was concerned, that was the professionalism, (...) then she cried (...) on the way home."* (Caregiver B)

Table 3 Identified themes and sub-themes

Theme	Sub-theme
The role of the caregiver	setting the caregiver role caregiver as a mainstay double role
I'll do everything for him / her	pain the mental and physical burden doubts spirituality
Support	professional support family support friends' support employment support
"Time out" after death	release of emotions after the death "time out" complicated mourning
Benefits of care	an intimate moment of death changing attitudes and values interest in palliative care preparing for your own death

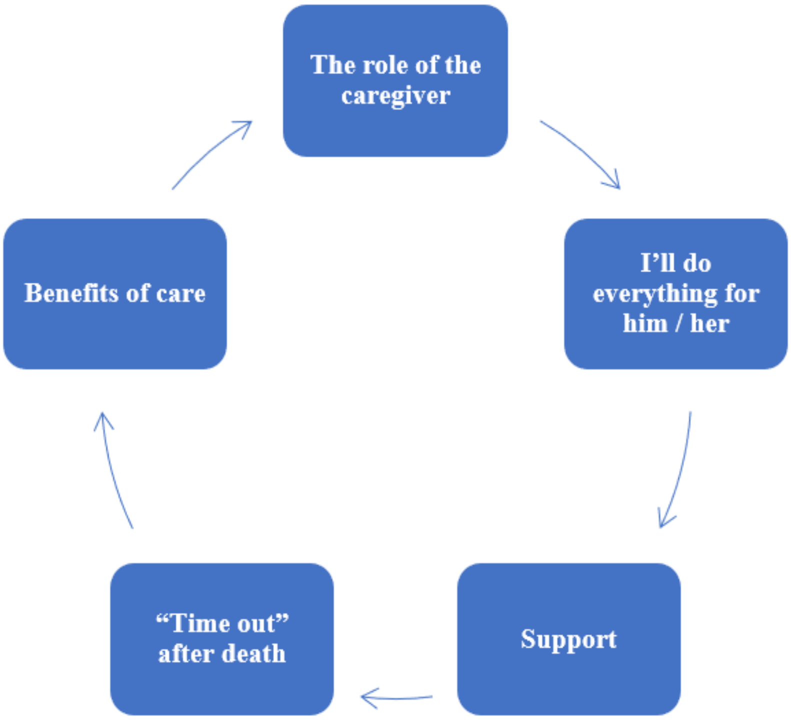

Figure 2 Thematic map of family caregivers' experiences

I'll do anything for him / her

This theme represents the very intensive stage of care when the patient's condition becomes terminal. Caregivers mobilize all their effort to ensure that they meet the needs of their loved ones in the last days of life. A separate sub-theme was *pain* and especially the management of severe or breakthrough pain. In some cases, caregivers lacked not only information but also medication to manage the growing pain.

The time they devoted to the dying was very demanding for the caregivers and represented a *mental and physical burden*, involving constant presence near the dying, isolation from other social ties, and insomnia, often accompanied by anorexia caused by permanent stress.

Some caregivers spoke of *doubts* and uncertainty about whether they had done the right thing when the patient was dying on heavy doses of opiates, without pain but incommunicado. The definitions of life, and the communication of impending death when asked by their loved ones, also raised questions: *"I know it helped her with the pain, but it didn't solve anything, and the communication was lost with her, yeah. That wasn't it, yeah. That I think she asked us, what's going on? When I was in the hospital in Přerov, she asked me if it was serious. But can you say that if we didn't know what was going on? But now, now I'm replaying everything, it's playing in me again, I'm just replaying everything – whether you did everything you could. If I should have just told her the truth. That I'm afraid ..."* (Caregiver D)

A *spiritual* aspect was involved in various forms for all participants. In two cases, a priest was called at the request of the dying person, and the family considered the moment to be very important and powerful for the dying person. Although they did not consider themselves practicing Christians, the priest's visit benefited the dying person and served as support for the caregiver herself.

Support

The theme of Support refers to the necessary *support for caregivers from professionals, family, and friends*, but also from *work*. In the initial period of care, fear and uncertainty dominate and later, physical difficulties. At this time, information and support are needed, especially from health professionals. The current generation of caregivers (50–65 years old), mostly tending to dying parents or partners, usually had no practical experience in caring for the seriously ill at home – they had not encountered dying at home. They felt support in the availability of a general practitioner they trusted, and in a practical demonstration of how to perform hygienic care and position the patient in bed. A human approach and expression of condolences from the EMS (Emergency medical services) after the death of a loved one also provided support. On the other hand, in some cases, caregivers also met with a lack of support from professionals, such as insufficient provision of pain medication or unprofessional handling of formalities related to the death of a loved one (e.g., when arranging the death certificate or widow's pension). Throughout, caregivers also appreciated family support and assistance, encouragement from close friends to share emotions, and support at work. The family respected the desire of the dying person to die at home and mutually respected the possibilities and limits of participation in care in the home environment of individual family members. In most cases, there was a kind of catharsis in the relationship between the dying and the caregiver, but also between the family members. There was also a high level of understanding and respect expressed in the interviews when other family members did not participate in the care directly, either due to workload, study obligations, or even the fear that they would not be able to manage the care. From the employer, the support was mainly in the form of temporary leave in the event of a change in the dying person's condition or the option of working from home: *"... and my cousin brought me a doctor, and she showed me in the future that she would actually take care of the caregiver dealing with such people. So, she was actually trying to show me how I would take care of her. (...) She showed me all sorts of tricks with a sheet, how to turn a person, just when it is not possible ... You know, I always say to myself that it's on a seesaw. I didn't go to work for two months after the death, she was still taking care of everything for my father – he is disabled, so everything. Now you are going around with a death certificate and it feels like ... well, what? (cries)."* (Caregiver D)

"Time out" after death

On the theme of "Time out" after death, caregivers commented on what followed after their loved one had died. Death caused a sudden and sometimes *unexpected release of emotions* that had been deliberately suppressed in front of the dying or other loved ones. The same caregivers described the state as a kind of timeless vacuum, a *"time out"* after the death of the loved one they had been caring for. Being present at the death helped them say goodbye to him / her with a sense of fulfillment. All caregivers whose parents died (Caregivers A, C, D) felt great loss. One even spoke of a state of "shock"

(Caregiver C). It took them all about a year to stabilize their lives. However, for one caregiver (C), the state of grief changed into a state known as complicated grief (in which some are so deeply affected by the death of a loved one that at some stage the usual process of grieving is arrested and they continue to suffer). Her pain, suffering, and sometimes even physical syndromes of a psychosomatic nature deepened and prevented her from continuing to function, affecting sleep, relationships, and ability to rest. Even after years, the memory of the deceased was still alive and the urn with the ashes kept in the house: *"I thought that if he was here, I might be grateful for every day with him, no matter what condition. He was in. Because, um, I still have a lot of things to say, yes. But on the other hand, I say to myself that I think that over time I did my best for him. Simply the best we could ... We really were done. We even did things that a person would not normallydo. And [a short pause] it's such that we're probably afraid to open it in the way that the ritual [storing the ashes with the urn – author's note] would be done, yes."* (Caregiver C)

Benefits of care

In the theme Benefits of care, caregivers spoke about how the experience of caring for the dying had changed their lives so far. Being present immediately at *the intimate moment of death* was an extraordinary benefit for them. They were grateful that they could be with the dying person until their "last breath". They experienced ambivalent feelings of loss mixed with relief. Also important was coming to terms with death, which was not experienced to the same extent by all family members: *"And as I stood by the chair, Dad actually looked at me, called me, and grabbed my hand (...). So, I stood by him the whole time. So, I sat down on a bit of that chair, yeah. (...) And Dad just leaned on me, looked. I know he told me he loved me so much. And he just closed his eyes and died. But you could see that he was happy – that he was relieved, yeah. It was terrible. For the first time in my life, I really saw both the nurse and the ambulance driver crying ... It was terrible ... hmm. It was touching, it was nice. At the same time, I was very relieved, but (short pause) ... I was probably just relieved to see that Dad was finally fine because he had suffered terribly that last day."* (Caregiver C)

They see a *change in attitudes and values* as a benefit – the family and the time devoted to it now have a higher value for them. They also described the reassessment of some existing attitudes in the sense of not judging others, accepting a different opinion, or a different behavior. There is more humility in their thinking. The newly acquired experience helped some develop in their professional lives, especially the general nurses. Overall, there was a clear *interest in palliative care* in the oral transmission of their experience. Finally, there was an awareness of their own future death and funeral, which also led to the arrangement of wills or an inventory of property: *"What did it bring me? I don't know any humility in life. Sure. I don't take some things for granted that I've taken so far. Yes, that I wake up every morning, that my whole family wakes up every morning, that I have themhere. So, we ... we all know that we are ... that we are not immortal. I really appreciate it every single day more since then. Hey, I don't take it for granted anymore. I also try to spend more time with my family."* (Caregiver A)

Discussion

The aim of this research study was to understand the experiences of family caregivers caring for a dying patient at home. Based on an interpretative phenomenological analysis, five main themes were identified in which family caregivers described their experience: the Role of the caregiver; I'll do everything for him / her; Support; "Time out" after death; and Benefits of care.

The results reflect the general consensus on the care of the dying person at home and also point to the emerging phenomenon of dying at home, which is newly returning to the Czech Republic. Although the resolution of the WHO's "Strengthening of palliative care as a component of comprehensive care throughout the course of life" from 2014 (WHO, 2014) emphasizes the promotion of quality palliative care to address the needs of dying patients, the results of our research show that between 2016 and 2018, when informal care was provided to a dying person at home, there was a considerable margin in support for family caregivers in the Czech Republic. Since 2018, when the reimbursement decree for palliative homecare services came into force in the Czech Republic, the number of providers of this care at home has increased. For a patient who meets the indication criteria for this reimbursement, the health insurance company, in the event of a contract with the given palliative homecare services, reimburses the care of a medical team consisting of a doctor and a nurse, available 24 hours a day. Thus, even when the patient's condition is unstable and there are serious symptoms such as pain, shortness of breath, vomiting, etc., the patient can remain at home for treatment and, when care is provided in this way, can be safely transferred to home from the hospital (The way home, 2018). Despite this significant help for informal caregivers, the main burden of care is on them.

Although it was not the intention to select participants caring for patients with a terminal oncological diagnosis, all four dying patients were dying of cancer of the gastrointestinal tract and the development of their disease was relatively rapid from the cessation of causal treatment and the transition to symptomatic treatment. The diagnosis of dying patients reflects the statistical incidence of these tumors in the Czech Republic, where, in international comparison, we occupy a leading position, and the incidence is relatively higher in the male population (Institute of Health Information and Statistics of the Czech Republic, 2021) in the long term. All caregivers in our sample were family caregivers. Almost two-thirds of long-term care in the Czech Republic is provided by women of middle or early retirement age, between 35 and 64 (Klímová Chaloupková, 2013).

In the initial phase of caring for a dying person, the caregiver takes on a new role in life – the role of the caregiver. This phenomenon of the decision to care has been described in various foreign research studies (Hughes, 2015; Kalnins, 2006; Linderholm & Friedrichsen, 2010; Perreault et al., 2004; Totman et al., 2015; Turner et al., 2016). According to Linderholm & Friedrichsen (2010), it is something automatic that does not need to be discussed. Our participants felt the same way when deciding to stay at home and care for the patient although there were also feelings of weakness and doubt and anxiety about how to cope with the new caring role. In the Czech Republic, there is a lack of direct experience of dying at home – according to research by the STEM MARK agency, 40% of the population and 80% of health professionals in the Czech Republic stated that people do not have direct experience of caring for a dying patient (The way home, 2011). Caregivers approach care with maximum commitment, although often they continue to have the same responsibilities for childcare, work duties, etc. They occupy various roles, while at the same time devoting maximum attention to the care of the dying person. Conflicts can easily arise due to the contradictory nature of these roles and the demands placed on the caregivers; on the one hand, the effort to "Do everything for him / her", on the other hand frustration at the hopeless situation of the approaching the death of a loved one and their own physical and psychological limits and ignorance. Our research confirmed the conclusions of Hajduchová et al. (2021) and Brémault-Phillips et al. (2016) that on the part of family caregivers, there is insufficient knowledge in the area of nursing competencies and a lack of information about possible available services, which, as a result, increases the physical and mental burden. This burden is a very common and well-studied phenomenon of caring for a dying person at home. The authors of a systematic review of qualitative studies focused on the experiences of family caregivers caring for a dying person at home, finding that caregivers' whole lives change. They experience physical fatigue resulting from the number of new tasks. They are burdened with emotions such as frustration, anger, sadness, and fear (Martín et al., 2016). The burden is also described in other foreign research studies (Jo et al., 2007; Perreault et al., 2004; Proot et al., 2003; Turner et al., 2016). None of the research participants reported financial stress associated with caregiving at home, although financial pressures are among the most serious concerns for many carers, and the financial burden of end-of-life caregiving can be substantial. In a critical debate paper, Gardiner et al. (2020) point out that the financial costs of informal caregiving at the end of life can be significant and include carer time costs, out-of-pocket costs, and employment-related costs. The financial burden is associated with a range of negative outcomes for both patient and caregiver. Evidence suggests that the financial costs of caring are not distributed equitably. Sources of inequity influencing access to specialist palliative care include diagnosis (cancer vs non-cancer), socioeconomic status, gender, cultural and ethnic identity, and employment status. According to research by Wang et al. (2022), caregivers who have any level of financial distress also reported poorer quality of life, greater burden, and feel less prepared for caregiving compared to caregivers with no financial issues. Younger caregivers are more prone to financial distress.

During care, family caregivers experienced respect for the patient's stated wish to die at home, for the support of health professionals, and for each other. This respect was an essential element of caring for a dying person. Family caregivers had a wide support network. The family served to share painful matters, to sustain each other in this situation, to provide relief from care, and to engage in care. Professional staff were supportive, providing practical help, answering questions about the next procedures, offering emotional support, and the guarantee of good care. Support for the patient and the family as a unit is important to the provision of high-quality palliative care. This entails education and guidance for patients and families about what to expect as function declines and the disease progresses. It also involves clarity over care expectations (Seow & Bainbridge, 2018). Friends supported family caregivers with practical help (e.g., shopping and babysitting) and emotional help. Support was also provided by employers, who accommodated the caregiver by limiting the number of hours at work. However, two participants reported experience of unsatisfactory communication with clinicians. According to Hudson et al (2004), it is of great importance that clinicians promote an environment that is conducive to optimal communication and information exchange. The outcome of these supportive strategies depends on how the clinicians can succeed in providing sufficient time for this communication. The support of friends and family is also mentioned in a foreign study by Turner et al. (2016), in which family and friends supported the caregiver emotionally and helped him / her with the daily tasks resulting from the care itself. The phenomenon of support is also described in a systematic review by Martín et al. (2016). The family caregivers were grateful for this support. Good relationships with family are key. They can openly express their fears and frustration, there is a redistribution of tasks, and they do not feel alone in their role. Lack of support disrupts care and increases the burden on the family caregiver. Informal care (short-term and long-term) and the issues of caregivers are important topics in Czech health and social policy and are included in the National Strategy for the Development of Social Services 2016–2025 (Ministry of Labour and Social Affairs of the Czech Republic – MoLSA CR, 2015). This form of care (informal family caregiver) is mentioned here as an extremely important part of the long-term care system since, according to qualified estimates, 70–90% of all social and health long-term care is provided by family members or other caregivers. Informal care has significant economic and social benefits. It fundamentally contributes to family cohesion and intergenerational solidarity. In areas with high unemployment rates it can reduce pressure on the labor market (MoLSA CR, 2015).

In the post-death period, most family caregivers needed time for themselves and took a break – “Time out” after death. They went somewhere with their family or alone. They no longer had to be the strong ones, so they gave free rein to the emotions they had suppressed inside. In our research, family caregivers did not report feelings of emptiness after the death of a loved one, as described by Linderholm & Friedrichsen (2010). They reported a sudden inner peace. Some family caregivers did not come to terms with the situation. They did not have time to say everything they wanted to the dying person. They developed symptoms of complicated grief, such as insomnia, constant thoughts of the deceased, and the inability to say goodbye. Family caregivers generally perceived the entire period of caring for a dying person as beneficial, even if demanding. They were ready to repeat it for another family member if necessary. This personal experience led to greater interest in this area, and a desire to deepen their knowledge of palliative care. In some cases, the experience of caring for a dying person led to the realization that the profession of helping was what they would like to pursue. Confronting the death of a person gave greater insight into mortality and preparation for one’s own death.

The last experience that gave great meaning to our family caregivers was the moment of death itself. The current generation of caregivers usually had had no practical experience in caring for a dying person at home. However, they perceived the death of a person as mystical and mysterious. They were with the dying person to the end. They held the hand of the dying person, were there with them in their final moments. They told them what they wanted to. After death, they wanted to be alone with the deceased for some time. The intimate moment of death is also described by Totman et al. (2015). In this research study, caregivers described anxiety about a person’s death and its incomprehensibility. They describe the big gap between knowing of death and actually experiencing it. As a result, they were confronted with their own mortality. However, the experience of caring for a loved one can also bring benefits to caregivers in their subsequent lives – benefits from care. All respondents of our research evaluated their care as blessing with hindsight, in contrast to an Australian study (Hudson et al., 2004), in which only 60% of caregivers rated care as a positive benefit. The positive impact appears to have increased over time due to the expanding network of palliative care support services for family caregivers. It has been state that the positive gains identified were similar to those described in the Western literature, such as satisfaction associated with the caregiving role, becoming a stronger person, and increased closeness with the patient (Aoun et al., 2005; Gill et al., 2003). The research study describes the significance of the experience of caring for a dying patient of four participants from the Czech Republic. This is an initial insight into this phenomenon in the Czech socio-cultural context. Although caring for a dying person is difficult and demanding, caregivers do not regret this experience and are ready to repeat it if necessary. The experience of caregivers shows important gaps in care that need to be addressed more in practice. This mainly concerns the need for professional support (providing / demonstrating equipment – positioning the bed, an oxygenator, practical demonstration of care, emotional support, financial support, the expression of condolences, provision of pain medication). It is important to support the family itself in the decision to care for the dying person at home.

Future research studies could involve a quantitative study design and investigate the needs of informal caregivers providing palliative care in the Czech Republic with a larger sample. It would be interesting to consider the stage of the disease and the perception of the imminence of death since these variables can affect the caregivers' emotional, cognitive, spiritual, and behavioral responses. Future research should also focus on other family caregivers besides spouses.

Limitation of study

Participants in this study were only those caregivers who were willing to share and talk about their experiences, which may not reflect the experiences of caregivers who did not want to participate in the study (Hagedoorn et al., 2008). Data collection using interviews was performed by both researchers, each with two participants, which could distort the course of the interview in terms of reflexivity. However, all were questioned according to the same interview protocol. A peer-auditing expert was not used for the given issue. Another possible limit was the relatively short length of the interview (45 minutes on average), influenced by respect for the sensitive content of the information the participants were willing to share. The nature of the interviews meant that participants revisited memories that had highly emotional content. In addition, the sample was from one urban setting and all participants were women, and participants were in a narrow age range (42–51 years). A final potential study limitation could be the previous inexperience of the first author in conducting qualitative interviews, although the first author was trained by an experienced team.

Conclusion

Using interpretative phenomenological analysis, five main themes were identified: The role of the caregiver; I'll do everything for him / her; Support; "Time out" after death; and Benefits of care. The identified themes describe the importance of the unique experience of caring for the dying at home. For caregivers, support from multiple sources is essential, but preferably comprehensive support from health professionals. The study shows unique family caregiver experiences in the Czech Republic. Confirming previous results, experiences are generally similar for all caregivers, pointing to a need for significant improvement in the quality of support and assistance from health professionals and support from family members, especially in areas of practical demonstration of care, the expression of condolences, provision of pain medication, handling of formalities related to the death of a relative (e.g., when arranging the death certificate and widow's pension), and sharing of emotions. Ultimately, the individual support options are based on personal assessment and depend on the particular situation in a family. The study will contribute to future studies investigating a similar topic within a framework of international relevance.

Ethical aspects and conflict of interest

The study was performed according to the Declaration of Helsinki. Signed informed consent of individuals to participation in the research survey was obtained by the researcher. Before signing the informed consent, respondents were informed that participation in the research was voluntary, anonymous, and that respondents had the right to withdraw from the study at any time.

The methodology of the research survey was approved by the Ethics Committee of the Faculty of Health Sciences of Palacký University in Olomouc (UPOL-2956/1040-2018).

The authors declare that the research study has no conflict of interest.

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Author contributions

Conception and design (LŠ, ŠŠ), analysis and interpretation of data (LŠ, ŠŠ), drafting of the manuscript (LŠ), critical revision of the manuscript (LŠ, ŠŠ), final finishing of the article (LŠ, ŠŠ).

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