

Experiences of being a severely ill parent of dependent children receiving care at home: Hopes and challenges

Original Article




Cite this article: Holm M, Lövgren M, Alvariza A, Eklund R, Kreicbergs U (2024). Experiences of being a severely ill parent of dependent children receiving care at home: Hopes and challenges. *Palliative and Supportive Care* **22**, 169–173. <https://doi.org/10.1017/S1478951523000184>

Received: 16 October 2022
Revised: 20 December 2022
Accepted: 12 February 2023

Keywords:

Parents; Palliative home care; Children; Communication; Intervention

Author for correspondence: Maja Holm, Department of Nursing Sciences, Sophiahemmet University, Box 5605, Stockholm 114 86 Sweden.
Email: maja.holm@shh.se

Maja Holm, R.N., PH.D.^{1,2} , Malin Lövgren, R.N., PH.D.^{2,3}, Anette Alvariza, R.N., PH.D.^{2,4} , Raket Eklund, R.N., PH.D.⁵ and Ulrika Kreicbergs, R.N., PH.D.^{2,6} 

¹Department of Nursing Sciences, Sophiahemmet University, Stockholm, Sweden; ²Department of Health Care Sciences, Palliative Research Centre, Marie Cederschiöld University, Stockholm, Sweden; ³Advanced Pediatric Home Care, Karolinska University Hospital, Stockholm, Sweden; ⁴Stockholm Sjukhem Foundation, Research and Development Unit/Palliative Care, Stockholm, Sweden; ⁵Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden and ⁶Department of Women and Child's Health, Karolinska Institutet, Stockholm, Sweden

Abstract

Objectives. Multiple studies have focused on severely ill patients in the role as parents of dependent children, yet few have explored the thoughts and feelings within this group during palliative home care.

Methods. This qualitative study derives from a pilot intervention study, the Family Talk Intervention (FTI), in specialized palliative home care. The FTI is a support program with the main goal to increase family communication about illness-related topics. The study is based on field notes from 104 sessions with 20 parents taken by an interventionist during intervention delivery. The field notes were analyzed using the principles of qualitative content analysis.

Results. The field notes revealed several challenging situations for parents with severe illness. A major issue was how to find ways to talk to their children about their illness and prognosis. The parents expressed guilt for being unable to fulfill their roles as parents and partners. Existing family conflicts had escalated with the illness, according to some parents. Despite being affected by illness, parents tried to have hope, if only for small things – such as a period of ordinary family life.

Significance of results. Severely ill parents in specialized palliative home care seek support regarding how to communicate and stay connected to their roles in the family, which is a struggle when a parent is cared for at home, while it in contrast may promote normality and hope. Communication with children is vital and needs to be brought to the attention of health-care professionals. A family-centered focus, involving both parents and children, should be embraced.

Introduction

Parents with severe illness and dependent children face a difficult and complicated situation, as they have parenting responsibilities while also facing the effects of their illness (Park et al. 2017, 2021). Research focusing on severely ill parents has been sparse and mostly in the area of cancer. Recent studies have concluded that communication with children about illness and death and maintaining family routines are major issues for severely ill parents (Alvariza et al. 2021; Holland et al. 2018; McCaughan et al. 2021). Compared with other patients, severely ill parents with dependent children are more worried, less likely to be peaceful, and 5 times more likely to experience panic disorder (Nilsson et al. 2009). They are often concerned for their children, which also contributes to symptoms of anxiety and depression (Park et al. 2016). Conversely, children are often deeply distressed by their parents' illness (Morris et al. 2016) and may have a great need for information and support from both their parents and health-care professionals (Eklund et al. 2020b; Patterson et al. 2017). Earlier studies have shown promising results for an intervention called the Family Talk Intervention (FTI), which focuses on communication and support in families with dependent children and a parent with severe illness (Alvariza et al. 2021; Eklund et al. 2020a, 2022). Participating families found the FTI to be well structured and adaptable to the needs of each family. They also stated that they would never have shared thoughts and feelings in a similar way without the intervention.

Thanks to medical developments, severe illness is no longer necessarily associated with imminent death, as many new therapies exist or are under development, contributing to prolonged life. However, this also means that patients live with severe illnesses for long and uncertain periods (Pizzoli et al. 2019). Severely ill parents usually want to maximize time with their children, and parental values and concerns may influence treatment preferences

(Check et al. 2017). Living with severe illness may also mean persistent physical symptoms and psychosocial concerns, navigating care alternatives, and possibly a lack of resources and support (Booker et al. 2021).

A trend in the care of severe illness is that patients are increasingly being cared for in their homes with the help of specialized palliative home care teams (Ailshire et al. 2021). This means that advanced forms of nursing and medical interventions and treatment such as infusions and symptom relief take place at home. It also means that the patient's family members become involved and often play a central part in providing help and support. In this context, little is known about what it is like to have a severe illness and be a parent of dependent children.

Aim

The aim was to explore the experiences of being a severely ill parent in receipt of specialized palliative home care.

Methods

Design

This work derives from a pilot study of the Family Talk Intervention (FTI) delivered in specialized palliative home care in Sweden. Data for this study were collected between March 2017 and February 2018. The intervention has been thoroughly described earlier (Eklund et al. 2018) and hence is described only briefly in this paper. The intervention focuses on facilitating family communication in families with dependent children, as well as on increasing knowledge about the illness, supporting parenting, and making children's needs visible. The intervention consists of 6 standard sessions led by trained interventionists. In this study, they were a social worker and a deacon from the Swedish hospital church. One of the interventionists had a more active role, whereas the other took field notes.

Participants

Families were recruited by social workers at 2 specialized palliative home care units in Stockholm, Sweden. Staffed round the clock by multi-professional teams, the units offered medical and nursing care for severely ill patients in their own homes. The inclusion criteria for families in the study were as follows: (1) at least one severely ill parent, (2) at least one child aged 6–19 years, and (3) ability to speak and write Swedish. If a family showed an interest in participating, they were contacted by phone by one of the interventionists. During this call, a meeting was arranged where the family received verbal and written information about the study and could give formal informed consent.

Data collection

Data for this study consisted of observational field notes that one of the interventionists took during the sessions. The interventionists had been instructed to write their field notes in as much detail as possible and to use the family members' own words in so far as possible. Generally, the transcripts were very detailed, with verbatim transcripts of conversations between families and interventionists. However, there were some notes that were more parsimonious, with general descriptions of the situation and dialogue. The length

of the notes varied from half a page to 7 pages of computer-written notes per session.

Because of the study aim, only field notes that focused on the ill parent were included, whereas notes focusing on partners and children were excluded. The analysis for this study was guided by the research question of experiences of being a severely ill parent in receipt of palliative home care.

Analysis

Data were analyzed using the principles of qualitative content analysis (Hsieh and Shannon 2005). The first and last authors had overall responsibility for the analysis. The field notes were first read through to get an overview of the content. Then, the 2 authors independently created codes based on the study aim: the experiences of the ill parent. After that, they compared their codes and found a high degree of agreement between them. In a second step, the 2 authors considered similarities and differences in the codes, resulting in the creation of categories. The codes were sorted into categories, and the authors reflected on the contents to refine the categories. In a third step, the entire group of authors read and commented on the codes and how they were sorted into categories, resulting in the final presentation of the result. Since the field notes were written by one of the interventionists, the result is partly based on their interpretations of the situations.

Results

Participant characteristics

In total, field notes from 104 sessions with 20 parents with severe illness (11 male and 9 female) were included in this study. They each had at least one child between 6 and 19 years. Of parents, 17 had a cancer illness, and 3 had another diagnosis (2 different forms of lung disease and chronic liver failure). The parents were between 39 and 60 years old.

The sample included 4 parents in single households and 7 parents who had children with more than 1 partner. One of the parents divorced her partner during the study. Four parents were born in other countries than Sweden. Three parents died during the process of data collection.

The experiences of being a severely ill parent being cared for at home

The analysis of field notes resulted in 4 categories. The field notes revealed that parents talked about the challenge of communicating their advanced illness with their children, described in the category *A wish to find a way to talk to the children*. They also had feelings of inadequacy toward the family for not managing to perform their usual chores or toward their partner and children, described in the category *Parenthood and guilt*. The category *Hope despite grief and despair* reflected how the parents talked about their attempts to be positive despite the grim prospects. The category *Escalating family conflicts* reflected parents' ways to describe how tensions in the family had increased with the illness. All 4 categories are described in greater depth below.

A wish to find a way to talk to the children

According to the field notes, during participation in the FTI, parents described communication regarding their severe illness, especially with their children, as a challenge. The entire family

experienced the illness at close quarters when the parent was being cared for in specialized palliative home care. Many parents had a desire for improved communication or for finding a way to talk to their children.

Several field notes revealed parents talking about the importance of being honest with their family and letting their children speak openly about their thoughts and feelings. It was noted that some parents talked about being unable to discuss their illness as it was too painful, whereas others had made an active decision to block out information about their prognosis. One father was unable to cope with the grief and feelings of others. He wanted to keep the subject of his illness to himself but nevertheless tried to provide answers when the family had questions.

Extract from field notes:

I can't deal with anyone who falls apart. I don't have the energy to comfort those who are down. We don't talk now. In the early days, we sat down and went over everybody's questions. If anyone asks anything now, I'll answer. But we don't have general family meetings. I think everyone has gotten the answers they need. I think they need an outside adult to talk to.

Openness in communication about other things than the illness could also be difficult. One of the parents was afraid to tell her children about a previous attempt at self-harm. Another parent feared telling her children that the illness was genetic and that they might carry the same gene.

It was noted that some parents mentioned that their children were not able to completely understand their illness and its consequences. Instead, these children reacted to the situation with anxiety, worry, and sometimes aggression, which took its toll on the parents.

Overall, the field notes revealed that communication seemed to be difficult, since each parent's prognosis was uncertain. Some knew that they would die soon, whereas for others, there was a chance of living for months or even years. Thus, it was challenging for the parents to answer questions from their children about death.

Parenthood and guilt

According to the field notes, parents described that their relationships with their children changed as the children went through different phases. The parents believed that their illness was a contributing cause of this, as well as their children's age and maturity. At times, the children reacted with anger and violence or by rebelling against parental authority. However, they could also crave more intimacy and attention. The emotional turmoil was challenging for the ill and fragile parents, who felt that they were not always able to respond to their children's emotional needs. Some parents had experienced that their children had nightmares and wanted to sleep close to them.

The field notes showed that parents of children with special needs, including neuropsychiatric disorders, were required to attend extra school meetings and provide special support to their children, which was exhausting during illness, and led to increasing delegation of such matters to their partners. Parents noted that their partners often carried a heavy responsibility for both the home and the children, which was frustrating. Parents stated that their energy levels did not allow them to fulfill their roles in the household, which made them feel guilty.

Consequently, as the parents were cared for at home, some witnessed that their children had to take more responsibility for the household, which caused worries that they were under too much pressure. In one family, an adult child was paid to do the cleaning.

An ill mother with 2 sons, one a teenager and one an adult, said that she depended a lot on the older son's assistance, as the younger son's father was not present in their life. The older son's help, for which she was very grateful, also made her feel guilty.

Extract from field notes:

I take time and strength from him, when I should be the one giving. Since I am the parent.

Hope despite grief and despair

According to the field notes, parents talked during the FTI about their hopes for a normal family life, if only for a short time, and being able to fulfill their roles as a partner and a parent. Being able to do chores in the home, spending time with the children, and supporting their partner were considered important and made them feel less like a burden to the family even when being cared for at home.

Grief was often talked about and documented in the field notes. The parents already grieved over things they would most likely miss out on, associated with a normal family life, such as seeing their children graduate, marry, and have children of their own. They felt that they had been robbed of a future that they had previously taken for granted. Still, many parents clung to the hope that they would be there at least until their children had grown up. A mother was concerned for her daughter's sake.

Extract from field notes:

She has the teenage period, with female matters. I asked who she can turn to and she just wants to talk to me... (crying).

Even though all parents were cared for at home, the field notes also revealed a lot about the illness trajectory, for example how parents had to go to a hospital to receive treatment, which often gave them feelings of anxiety and fatigue, even though they wanted to keep their hope alive. This, along with pain, fear, and grief, sometimes made them feel it would be better if their lives were to end right away. Their desire for death made them feel shame and that they had no right to feel that way when they had children who needed them. They also had feelings of being a burden to other family members. The physical and mental pain that their illness caused them added to this feeling.

Escalating family conflicts

Field notes revealed that some parents had experienced family tensions before the illness, but that these had escalated with the advancing illness and the ill parent's care at home. Conflicts between the children were tiresome for the ill parents and led to strains with their partners.

Extract from field notes:

The relationship is affected by the kids, conflicts between the kids, we have differing views. The worst part is the lack of willpower to help out.

According to the field notes, families with constellations including stepparents and stepchildren found it difficult to balance the needs of all the family members and manage conflicts between children or between new partners and children. Still, some parents had the same feelings for their stepchildren and their biological children.

In some families, parents were in conflicts with their former partners who were co-parents of their children. Some parents considered their former partners unfit to take care of their children, due to a history of violent behavior, mental illness, or substance abuse. Having a severe illness and being forced to worry that the

children would suffer at the hands of the other parent if they themselves died was a source of deep concern.

The field notes showed that parents talked about financial difficulties due to their illness. This could be a source of conflict in the family, both between a parent and their partner and between parents and children. Single-parent households were especially vulnerable to financial difficulties and needed help to navigate the welfare system to receive financial support.

Discussion

This study focused on the experiences of severely ill parents of dependent children who were being cared for in specialized palliative home care. To the authors' knowledge, this has not been explored earlier in research; however, many of the challenges described in field notes in this study have been found in earlier studies, especially in the context of oncology care (Park *et al.* 2017; Rashi *et al.* 2015). For example, common findings were made regarding the difficulties of balancing parental responsibilities and coping with the illness. Park *et al.* described how ill parents defined themselves as "bad" for being unable to fulfill their parental responsibilities (Park *et al.* 2017). In our study, parents also felt guilty for being a burden to their entire family, something that could have become more evident in the home environment. It has been reported that maintaining everyday routines could be a way for families living with severe illness to achieve ordinariness in an extraordinary situation (McCaughan *et al.* 2021). This was also an issue for parents in our study, where they described that they desired a normal family life at home, if only for a while.

Many field notes focused on family communication and the difficulty of putting into words the severity of the illness and the uncertainty in daily family life at home that came with it. Earlier results have found that parents are often afraid of causing harm to their children by informing them about their illness, although it has been consistently reported that children wish for clear and honest information (Dalton *et al.* 2019). Parents expressed the need for support from health-care professionals to manage such communication (Fearnley and Boland 2017). Rather than being overprotected, children want and need to be involved in their parent's life and play an active part in caregiving (Marshall *et al.* 2022), something that could be especially important when a parent is cared for at home, where parents and children are together for much of the time. Health-care professionals have an important role in including children in family-centered care and not excluding them from information and conversations about a parent's severe illness (Marshall *et al.* 2021).

Despite illness and the hardship that comes with it, not only for the parent but also for the family, hope was a companion to the parents. They wanted to believe that life would go on, if only for a while, especially for their children's sake. Receiving care at home was one way to keep hope of normality in life. Hope in parents with severe illness could be a way to affirm the value of family life and may also coexist with uncertainty and awareness of the illness (Borneman *et al.* 2014). In a previous study of mothers with cancer, participants stated that their illness also came with positive aspects, reminding them to live each day to the fullest and to be grateful for simple things (Loggers *et al.* 2019).

In the field notes, family conflicts of various kinds were described and said to escalate with the seriousness of the illness. It may be a result of a parent being cared for at home. Earlier results have described home-based family caregiving at the end of life as involving intense, conflicting, negative, and/or difficult

emotions (Funk *et al.* 2010). Interventions like the FTI, which aims to improve communication and awareness among family members, might be a starting point for a process of improved communication, although this may not be enough to solve family conflicts. Considering the nature of some of these conflicts, some families might need more thorough professional interventions or even family therapy to cope with daily life. Such interventions could expand supportive care for patients and their children (Hailey *et al.* 2018).

Strengths and limitations

The strengths of this qualitative study include a varied sample, encompassing different family constellations and people from different cultures – not only those born in Sweden – which contributes to its trustworthiness. Earlier research has highlighted that most studies on families when a parent has a serious illness have included middle-class, two-parent, Western-culture families (Pinto and Pinto 2021), which was not the case in this study, although the families all had heterosexual parents. Furthermore, the field notes that constituted data for the study were rich and detailed and most were taken in the home environment, where the participants would arguably feel most comfortable. This is visible in the field notes and seems to have added to the richness of the data.

However, a limitation is that the field notes may not necessarily reflect the situation as they were not recorded or filmed, but taken down by an interventionist. This means that they were not exact transcripts but rather depended on the interventionist's individual abilities and experiences.

Conclusion

This study highlights the experiences of severely ill parents of dependent children receiving care at home. The challenges these parents face are similar to what has been found in studies in other contexts. However, the home care context could make the challenges especially intense, such as upholding their parental responsibilities and how to manage communication and conflicts in the family. Despite these challenges, many parents clung to hope and found comfort in ordinary family life, something that being cared for at home allowed them to continue with.

The results from the field notes illuminate that parents and families need support in how to communicate and fulfill their roles to maintain normality and hope for as long as possible. Family-centered care encompassing the entire family could contribute to this and thereby improve such situations, not only for the parents but also for the family, in both a short- and long-term perspective. However, the results of this study also demonstrated many complex situations and family conflicts, indicating a need for more tailored support from professionals.

Acknowledgments. We wish to thank the participants for generously sharing their experiences.

Conflicts of interest. None declared.

Ethical approval. Ethical approval was obtained from the Regional Ethical Review Board in Stockholm (approval numbers 2016/664-31/5 and 2017/7-31/1).

References

Ailshire J, Osuna M, Wilkens J, *et al.* (2021) Family caregiving and place of death: Insights from cross-national analysis of the harmonized end-of-life

- data. *The Journals of Gerontology: Series B* 76(Suppl 1), S76–S85. doi:10.1093/geronb/gbaa225
- Alvariza A, Jalmsell L, Eklund R, et al.** (2021) The Family Talk Intervention in palliative home care when a parent with dependent children has a life-threatening illness: A feasibility study from parents' perspectives. *Palliative & Supportive Care* 19(2), 154–160. doi:10.1017/S1478951520000735
- Booker R, Bays S, Burnett L, et al.** (2021) Supporting people and their caregivers living with advanced cancer: From individual experience to a national interdisciplinary program. *Seminars in Oncology Nursing* 37(4). doi:10.1016/j.soncn.2021.151169
- Borneman T, Irish T, Sidhu R, et al.** (2014) Death awareness, feelings of uncertainty, and hope in advanced lung cancer patients: Can they coexist? *International Journal of Palliative Nursing* 20(6), 271–277. doi:10.12968/ijpn.2014.20.6.271
- Check D, Park E, Reeder-Hayes K, et al.** (2017) Concerns underlying treatment preferences of advanced cancer patients with children. *Psycho-Oncology* 26(10), 1491–1497. doi:10.1002/pon.4164
- Dalton L, Rapa E, Ziebland S, et al.** (2019) Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent. *The Lancet* 393(10176), 1164–1176. doi:10.1016/S0140-6736(18)33202-1
- Eklund R, Alvariza A, Kreicbergs U, et al.** (2020a) The family talk intervention for families when a parent is cared for in palliative care – Potential effects from minor children's perspectives. *BMC Palliative Care* 19(1), 50. doi:10.1186/s12904-020-00551-y
- Eklund R, Kreicbergs U, Alvariza A, et al.** (2018) The family talk intervention in palliative care: A study protocol. *BMC Palliative Care* 17(1), 35. doi:10.1186/s12904-018-0290-8
- Eklund R, Kreicbergs U, Alvariza A, et al.** (2020b) Children's self-reports about illness-related information and family communication when a parent has a life-threatening illness. *Journal of Family Nursing* 26(2), 102–110. doi:10.1177/1074840719898192
- Eklund R, Lovgren M, Alvariza A, et al.** (2022) Talking about death when a parent with dependent children dies of cancer: A pilot study of the Family Talk Intervention in palliative care. *Death Studies* 46(10), 2384–2394. doi:10.1080/07481187.2021.1947415
- Fearnley R and Boland JW** (2017) Communication and support from health-care professionals to families, with dependent children, following the diagnosis of parental life-limiting illness: A systematic review. *Palliative Medicine* 31(3), 212–222. doi:10.1177/0269216316655736
- Funk L, Stajduhar K, Toye C, et al.** (2010) Part 2: Home-based family caregiving at the end of life: A comprehensive review of published qualitative research (1998–2008). *Palliative Medicine* 24(6), 594–607. doi:10.1177/0269216310371411
- Hailey CE, Yopp JM, Deal AM, et al.** (2018) Communication with children about a parent's advanced cancer and measures of parental anxiety and depression: A cross-sectional mixed-methods study. *Supportive Care in Cancer* 26(1), 287–295. doi:10.1007/s00520-017-3847-9
- Holland C, Hocking A, Joubert L, et al.** (2018) My kite will fly: Improving communication and understanding in young children when a mother is diagnosed with life-threatening gynecological cancer. *Journal of Palliative Medicine* 21(1), 78–84. doi:10.1089/jpm.2017.0058
- Hsieh HF and Shannon SE** (2005) Three approaches to qualitative content analysis. *Qualitative Health Research* 15(9), 1277–1288. doi:10.1177/1049732305276687
- Loggers ET, Kirtane K, Palacios R, et al.** (2019) Leaving footprints, not scars: A qualitative pilot study of Hispanic mothers' willingness to communicate with dependent children about an advanced cancer diagnosis. *Supportive Care in Cancer* 27(4), 1573–1578. doi:10.1007/s00520-018-4576-4
- Marshall S, Fearnley R, Bristowe K, et al.** (2021) The perspectives of children and young people affected by parental life-limiting illness: An integrative review and thematic synthesis. *Palliative Medicine* 35(2), 246–260. doi:10.1177/0269216320967590
- Marshall S, Fearnley R, Bristowe K, et al.** (2022) 'It's not just all about the fancy words and the adults': Recommendations for practice from a qualitative interview study with children and young people with a parent with a life-limiting illness. *Palliative Medicine* 36(8), 1263–1272. doi:10.1177/02692163221105564
- McCaughan E, Semple CJ and Hanna JR** (2021) 'Don't forget the children': A qualitative study when a parent is at end of life from cancer. *Supportive Care in Cancer* 29(12), 7695–7702. doi:10.1007/s00520-021-06341-3
- Morris JN, Martini A and Preen D** (2016) The well-being of children impacted by a parent with cancer: An integrative review. *Supportive Care in Cancer* 24(7), 3235–3251. doi:10.1007/s00520-016-3214-2
- Nilsson ME, Maciejewski PK, Zhang BH, et al.** (2009) Mental health, treatment preferences, advance care planning, location, and quality of death in advanced cancer patients with dependent children. *Cancer* 115(2), 399–409. doi:10.1002/cncr.24002
- Park EM, Check DK, Reeder-Hayes KE, et al.** (2017) Parenting while living with advanced cancer: A qualitative study. *Palliative Medicine* 31(3), 231–238. doi:10.1177/0269216316661686
- Park EM, Deal AM, Check DK, et al.** (2016) Parenting concerns, quality of life, and psychological distress in patients with advanced cancer. *Psycho-oncology* 25(8), 942–948. doi:10.1002/pon.3935
- Park EM, Jensen C, Song MY, et al.** (2021) Talking with children about prognosis: The decisions and experiences of mothers with metastatic cancer. *JCO Oncology Practice* 17(6), e840–e847. doi:10.1200/Op.21.00003
- Patterson P, McDonald FEJ, White KJ, et al.** (2017) Levels of unmet needs and distress amongst adolescents and young adults (AYAs) impacted by familial cancer. *Psycho-oncology* 26(9), 1285–1292. doi:10.1002/pon.4421
- Pinto C and Pinto S** (2021) When a parent is dying: How we can do more to support families and children with a dying parent. *Evidence Based Nursing* 24(1), 4. doi:10.1136/ebnurs-2019-103192
- Pizzoli SFM, Renzi C, Arnaboldi P, et al.** (2019) From life-threatening to chronic disease: Is this the case of cancers? A systematic review. *Cogent Psychology* 6(1), 1577593. doi:10.1080/23311908.2019.1577593
- Rashi C, Wittman T, Tsimicalis A, et al.** (2015) Balancing illness and parental demands: Coping with cancer while raising minor children. *Oncology Nursing Forum* 42(4), 337–344. doi:10.1188/15.ONF.337-344