Support Care Cancer (2004) 12:120–128
DOI 10.1007/s00520-003-0569-y

ORIGINAL ARTICLE

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Next of kin's experience of powerlessness and helplessness in palliative home care

Received: 2 June 2003
Accepted: 30 October 2003

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Abstract *Goals of work:* Powerlessness and helplessness have been very little studied. The aims of this study were (1) to describe what characterise such experiences and the meaning of them to next of kin of cancer patients in advanced palliative home care and (2) to make quantifications. *Patients and methods:* The study design was cross-sectional and targeted next of kin during ongoing palliative home care and next of kin of patients who had died 3–9 months earlier; 233 next of kin responded (response rate 72%) to a postal questionnaire with both Likert-type and open-ended questions. The text responses were analysed with a combined qualitative and quantitative content analysis. *Main results:* Thirty-six percent of respondents stated that they had experienced powerlessness and/or helplessness every day or several times per week, whereas 33% had never had this experience during the palliative home care period. Powerlessness and helplessness concerned next of kin's perception of the patient's suffering, of the patient's fading away and the next of kin's own feelings of insufficiency and resulted in both physical and psychological symptoms, such as muscle tension, headache, loss of appetite, anxiety and depression. In addition, powerlessness and helplessness concerned also a deeper meaning with existential and social aspects, such as feelings of guilt, anger and loneliness. *Conclusions:* The main findings provide tools for the practitioner to identify situations contributing to next of kin's sense of powerlessness and helplessness. The findings are discussed in relation to the concepts of symptom control, communication of awareness and humans' search for action.

Keywords Next of kin · Palliative care · Powerlessness · Helplessness

Introduction

"To see one's beloved being eaten up from inside, to sit alongside and wait for time to pass—that is murdering." (A 63-year-old husband to a dying patient with pancreatic cancer describing his experience of powerlessness.) This quotation is typical of many of the informants in this study.

In a study that we recently conducted where meaninglessness, comprehensibility and manageability in cancer patients' next of kin in palliative home care were explored [54], several participants used the word "powerlessness" in combination with deep frustration when they described their situation. This made us interested, and we decided to study the phenomenon further. However, during the questionnaire development, it turned out that there was no clear, useful definition of powerlessness (*vanmakt* in Swedish), neither in dictionaries nor in the research literature. Instead, next of kin, lay people, clinicians as well as researchers used the concept as partly overlapping with that of helplessness. Such overlapping use of the concepts was also present in the research literature [10, 20, 44, 73, 76, 57], and the lack of clear definitions had been pointed out by others [13]. Although theoretical clarifications of the concepts have been suggested [13], they did not seem applicable in communication with lay people and their use of the words in everyday language. Therefore, we chose to expand the initial study phenomenon to include helplessness.

A literature search confirmed both concepts' relevance within health care. A considerable amount of literature has illuminated the presence of powerlessness and helplessness in the workplace of nurses [14, 23, 56, 58, 59, 81] and doctors [52]. Patients' suffering from chronic illness as well as progressive malignant disease [7, 9, 24, 32, 40, 71] and the next of kin's experiences have also been described in terms of powerlessness and helplessness. Such experiences have been illuminated in different groups of next of kin, for example parents having a disabled child [20], parents of stillborn children [41, 49, 64], informal caregivers of patients with chronic diseases [11] and cancer patients [18, 46], and also within home care [11, 79]. In fact, Ruppert stated that powerlessness is indeed one of the most frequently related psychological aspects related to the caregiving experience [61].

There are limited studies within a palliative context of these phenomena, although the concepts' relevance within palliative home care have been stressed [79]. Lindholm et al. showed that significant others of women with breast cancer experienced powerlessness [46], and Ferrell et al. described that families of women with ovarian cancer perceived helplessness [18]. Such experiences have been described in relation to patients' pain [17, 51, 53], and also as a lack of control [18].

Powerlessness has in fact by some authors been conceptualised as the opposite of mastery, that is, the counterpart of mastery and control [69]. Lack of control is also a core feature in the "learned helplessness theory of depression" in a study by Seligman et al. [70]. This theory suggests that sufficient exposure to uncontrollable events, such as the sudden loss of a spouse, leads to an altered set of expectations about self-efficacy that impair later coping in the face of challenge [57].

From an existential viewpoint, powerlessness has been described in relation to existential isolation (the ultimate intrapersonal isolation, as opposed to an interpersonal social isolation). As psychiatrist Yalom wrote: "To relinquish a state of interpersonal fusion means to encounter existential isolation with all its dread and powerlessness. The dilemma of fusion-isolation—or, as it is commonly referred to, attachment-separation—is the major existential developmental task" [84].

Both powerlessness and helplessness have been connected to depression [27, 4]. In fact, helplessness has been pointed out as one criteria of depression in terminally ill patients [4] and as one of several core phenomena in demoralisation syndrome [40]. Demoralisation syndrome has been described as a persistent inability to cope, together with associated feelings of helplessness, hopelessness, meaninglessness, subjective incompetence and diminished self-esteem [8]. According to Clarke and Kissane, the syndrome is of clinical relevance in palliative care and, in addition, "it is arguably the main reason people seek psychiatric treatment, yet is a concept largely ignored in psychiatry" [8, 40]. The concepts of powerlessness and helplessness may also provide prospective predictions concerning health, as indicated by the increased sense of powerlessness that accompanied deterioration in health among older men and mature women [69], and later adjustment disorders among family caregivers that had perceived helplessness when taking care of a dying person [75].

So, experiences of powerlessness or helplessness may impact next of kin's health, and research has shown that next of kin's health is influenced in a negative way when caring for a dying family member or friend [31, 42, 63]. The possibility of staff interventions in reducing next of kins' feelings of powerless or helplessness has not been further studied within a palliative context. However, there are some indications of such potential, as shown by Yalom in his work with cancer patients' feeling of powerlessness in relation to their physicians. When patients were helped in group therapy to assume responsibility for their relationship to their doctor, they developed a sense of potency [84]. In addition, a revision of the "learned helplessness theory" indicated that even when events are uncontrollable, people can perceive, and also learn, that they have some control, i.e. "illusions of control", which have functional value in reducing stress [57].

It seems important to increase understanding of the concepts and, when possible reduce, powerlessness and helplessness in the context of palliative care, because next of kin are often a prerequisite for successful palliative home care and fulfilment of the patient's wish of remaining at home despite approaching death [26, 29]. Although studies indicate high clinical relevance of powerlessness and helplessness, there is lack of studies quantifying the concepts' abundance in the palliative context. In addition, there is no contextual description of the concepts in palliative care to facilitate staff's recognition of such situations, that is, what characterises situations that trigger feelings of powerlessness or helplessness in palliative care and the meaning of such feelings to next of kin.

The overall aim of this postal questionnaire was to illuminate the experience of powerlessness and helplessness in a palliative home care context from the perspective of next of kin by asking the following questions: "When do next of kin experience feelings of powerlessness and/or helplessness and when do they not?" "What is the meaning of such feelings to next of kin?" "What increases and decreases such feelings?" "How common is it?". Due to the rich material we got from the responding next of kin, the aim in this article will be restricted to those presented below, and the other findings will be presented elsewhere:

- To describe powerlessness and helplessness according to next of kin of cancer patients in advanced palliative home care (APHC) with regard to what characterises such experiences and the meaning of them to next of kin.
- To quantify the percentage of next of kin who have experienced powerlessness and/or helplessness during APHC.

Patients and methods

Study population

The study population (mainly spouses) consisted of 233 responding next of kin of cancer patients who were recruited from three APHC teams in Sweden. Next of kin was defined as the person that was identified by the patient (and noted in the medical record) as being the person primarily involved in the care of the patient in the home setting [43]. The study design was cross-sectional and targeted two groups of cancer patient's next of kin: (1) those during ongoing palliative home care and (2) those where the patient had died 3–9 months before. Next of kin of patients that had died merely 1–3 months earlier were excluded due to the risk of burdening them, as the realisation of what it is like to live without their loved one often begins to emerge around 3–4 months after the loss [82].

All three teams had a similar palliative care organisation according to the Swedish model with a multi-professional team, 24-hour services, access to a back-up ward, and, in contrast to several other models, there was access to a medical doctor around the clock [3, 60]. Ninety-eight percent (149/152) of the cancer patients' next of kin during ongoing care and 97% (174/180) of next of kin during 3–9 months bereavement were mailed the study questionnaire. Reasons for exclusions and attrition (*n*=3 during ongoing care and *n*=6 during bereavement, respectively) were due to unknown addresses, language problems and lack of a close relative. Characteristics of the respondents are presented in Table 1.

Data collection and analysis

As pointed out in the "Introduction", the initial focus was on powerlessness. However, due to the interrelated use of powerlessness and helplessness in everyday language and in research literature, as well as lack of applicable definitions, we chose to expand the study phenomenon to include both powerlessness and helplessness as interchangeable terms. The combination of the two Swedish words (*vanmakt* and/or *hjälplöshet*) covers conceptually both the state of being powerless or helpless and the profound associated feeling of frustration.

A questionnaire was constructed with focus on open-ended questions where the next of kin were asked to describe their experiences of powerlessness and/or helplessness in their own words, as well as to provide a concrete example of a situation. Additional questions concerned background data of the next of kin and the patient, overall assessment of the support from APHC (5-grade Likert-type; from "very bad" to "very good"), frequency of feelings of powerlessness and/or helplessness (5-grade Likert-type; from "every day" to "never").

The overall design of the open-ended questions was inspired by the qualitative interview technique where the informants are asked to share a concrete situation in which he/she experienced the study phenomenon (in this study powerlessness and/or helplessness) [45]. The next of kins' descriptions of their experiences were guided by open-ended questions: "Would you like to describe a situation where you have experienced powerlessness and/or helplessness?" "What have the feelings of powerlessness and/or helplessness meant to you during ongoing care and (to the bereaved) afterwards?" ("How did you manage the situation?" "Did it help?" "Could health care have facilitated or prevented that situation?" "In what way?" Those who never or seldom experienced powerlessness and/or helplessness were asked: "What has helped you to escape from feeling powerless and/or helpless?). The findings related to the questions within parenthesis will not be illuminated in this presentation, as explained in the "Introduction".

Table 1 Characteristics of the study population of next of kin, their relation to the cancer patients and characteristics of the cancer patients. The study population consisted of two types of next of kin: (1) next of kin of cancer patients during ongoing advanced palliative home care (APHC) and (2) next of kin of cancer patients that had died during care in APHC 3–9 months previously

	Total	Ongoing palliative care	Bereavement
Characteristics of the next of kin			
Next of kin that was mailed questionnaire (*n*)	323	149	174
Respondents (*n*)	233	99	134
Response rate (%)	72	66[a]	77
Female/male/unknown (%)	62/37.5/0.5	54/45/1	70/30/0
Respondents' age in years—median (range)	65 (31–91)	65 (34–91)	65 (31–91)
Respondents relation to the cancer patients			
Husband, wife or cohabitant (*n*)	158	72	86
Child/sibling/parent/other (*n*)	51/11/5/8	17/5/2/3	34/6/3/5
Characteristics of the cancer patients			
Female/male/unknown (*n*)	108/124/1	59/ 39/1	49/85/0
Patients' age—median value in years (range)	73 (23–94)	71 (36–92)	75 (23–94)
Duration of APHC (months): 0–3/3–6/>6/unknown (*n*)	98/54/52/21/8	30/ 24/31/10/4	68/30/21/11/4
Lung/G-I/prostate/liver/pancreas/breast/brain/other (*n*)	36/31/29/23/20/14/11/37	15/12/7/2/9/10/9/16	21/19/22/21/11/4/2/21
Unknown origin to next of kin/not responded (*n*)	30/2	18/1	12/1

[a] 31 of the patients died between the date when the first questionnaire was posted and the date when the reminder was to be sent, and no reminder was sent to those next of kin

Content validity was checked by clinicians (MDs and nurses experienced in palliative care and oncology) and researchers who were not otherwise involved in the development of the questionnaire, both through personal contacts and in a seminar. In addition, the questionnaire was distributed to three next of kin in meetings with one of the authors (AM). This pilot study showed that next of kin had no difficulties in filling in the questionnaire, and only minor changes were made mainly due to an ambiguous phrasing that was removed. The main part of the questionnaire consisted of the open-ended questions, and the other quantitative part consisted, except background variables, of four Likert-type questions concerning next of kins' overall assessment of the support from APHC and frequency of feelings of powerlessness and/or helplessness. For ethical reasons, we decided not to burden the next of kin with a test-retest manoeuvre of these four Likert-type questions. Due to the semantic problems with the interrelated use of the words powerlessness and helplessness, as described in the "Introduction", there was no gold standard or relevant other similar measures to test criterion and construct validity.

The questionnaires were posted at different dates to the six different groups of next of kin (three cities, both to next of kin during ongoing advanced palliative home care and to next of kin 3–9 months after a patient's death), so we got responses from the first group before we had posted to the second one. This extra pilot study showed that the questionnaire seemed to work well, with rich responses to the open-ended questions and distribution of the responses over the Likert scales, and therefore, no further changes were made.

Next of kin were identified through an existing clinical database and were mailed an invitation letter, an uncoded questionnaire and a pre-paid envelope addressed to the Palliative Research Unit. The questionnaires were uncoded to ensure anonymity. A reminder was sent after 2 weeks to all next of kin. Data were collected between December 2001 and August 2002. The study was approved by the regional ethics committee, which means that all routine standards set for questionnaire studies were fulfilled.

Responses to the open-ended questions were initially analysed using qualitative and quantitative content analysis with no preconceived codes [55, 77]. Content analysis was chosen because this method allows a combination of both a qualitative and a quantitative approach. The applicability of this approach as a method for analysis of open-ended questions in questionnaires has been described previously [28]. In fact, a combination of a qualitative analysis with some quantitative summary of the results has been suggested as a way of minimising researcher bias in the presentation of the results [50].

Coding and development of categories were mainly done by the first author, and the co-authors concentrated on the validation of results. Every response was read through by two authors, and the categories were discussed until agreement was reached. The analysis was performed using the following steps: First, all responses were read through to obtain an overall picture and to develop themes. Second, the responses were re-read systematically, line by line, to identify significant text segments and develop matching codes and preliminary categories. The actual words written by next of kin were used to as great an extent as possible. Third, the statements in each preliminary category were scrutinised and compared to find their central component. Fourth, the final categories were compared to avoid obvious overlapping, and content descriptions and relations to other categories were developed.

Intercoder reliability was calculated (percent agreement between the coders). Almost one-fourth of the questionnaires (ongoing care *n*=24/99; during bereavement *n*=31/134) were randomly assigned and coded blindly by the second author using the set categories by the first author, and intercoder reliability was calculated. "Full reliability" (total agreement in categories used) and "partial reliability" (no contradictory coding, but one author had used additional categories in coding the responses) were calculated and were as follows: 95% full agreement and 5% partial agreement.

Results

The frequencies concerning next of kin's experience of powerlessness and/or helplessness are presented in Fig. 1. Two hundred four of the 233 next of kin who returned the questionnaire also responded to the open-ended questions. Powerlessness and/or helplessness was described as a strong multi-faceted feeling, and four main components emerged in the analysis: (1) perception of patient's suffering, (2) perception of patient's fading away, (3) feeling of insufficiency and (4) reactions and deeper meaning.

Perception of patient's suffering

A central component of next of kins' feeling of powerlessness and/or helplessness was their perception of patient suffering. Different dimensions of suffering were described, including traditional physical and psychological symptoms, such as pain, fatigue, breathlessness, depression and anxiety, which added to a profound feeling of powerlessness in next of kin. Social and existential suffering were also mentioned, such as impaired function in daily life, reduced autonomy and loneliness. Loneliness concerned the patient living, suf-

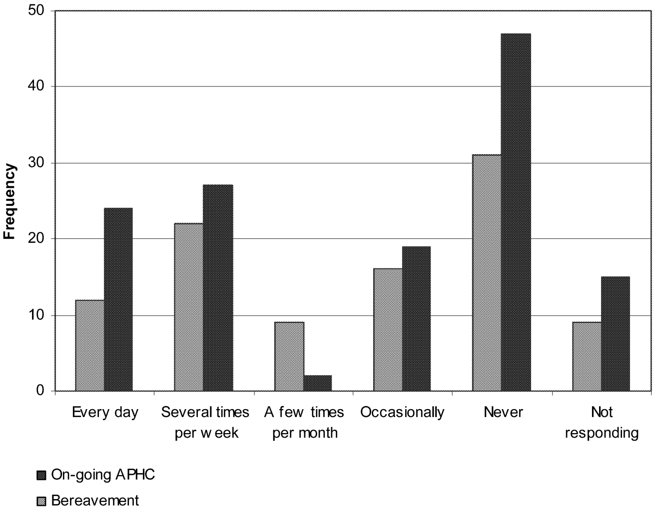

Fig. 1 Next of kin's experience of powerlessness and/or helplessness during advanced palliative home care (APHC). Both next of kin during APHC and next of kin of the patients that had died 3–9 months previously were asked if and how often they experience/had experienced powerlessness and/or helplessness during APHC. There was no difference between the two groups according to Mann-Whitney *U* test (p>0.9)

fering and dying alone, i.e. physical, social and even existential aspects of loneliness. Situations that had triggered next of kins' perception of patient suffering were different kinds of leave-takings, poor symptom control and deterioration of the patient's health.

Every time I saw that there was a change for the worse in mum, from one day to another (I felt powerless). She couldn't manage to get up from a chair or the toilet. She stepped into the bathtub at home to shower by herself, and she was almost unable to get out of there and she didn't press the alarm because she waned to get on by herself, she didn't want to be a bother. . . . It still drives me to despair when I think of how she was alone with her thoughts much too much. . . . Every time we left mum after some hours' visit, it was hard knowing that she was alone.

(A 42-year-old child of a 65-year-old cancer patient.)

"Every time, often several times a day, he said 'I don't want to die'. He repeated 'Why cancer, and why me'. By the end, when his strength ebbed away and he couldn't manage to sit down on the toilet; when he hardly managed to cough". (The wife of a 75-year-old cancer patient.)

Perception of patient's fading away

A second main component in next of kins' feeling powerlessness and/or helplessness was their perception of the patient's fading away. This was described in vivid terms/metaphors as a result of either the patient's own declining strength or outer destructive forces, such as the cancer eating from inside. However, only eight of the next of kin during on-going APHC and 23 of those during bereavement explicitly stated the actual words "death" or "dying" in their responses. The disappearance concerned different dimensions of the patient as a human being, i.e. negative changes as regards the patient's body, strength, functions and individuality. Perception of the patient's fading away had a clear temporal component, i.e. the perception of patient's disappearance started in the past and was to continue in the future in contrast to the perception of the patient's suffering that was in the here and now. Triggering situations included breakpoints when it had been obvious to the next of kin that the patient's health had deteriorated, e.g. when receiving information that chemotherapy was going to be ended due to disease progression.

"The worst is, of course, seeing how a dear member of my family just gets more and more tired, worse and worse, and just pines away. Although I try to cook food he likes and can eat. But still, it does not help". (The 68-year-old wife of a patient with generalised cancer.)

Feeling of insufficiency

Perception of the patient's suffering and fading away both contributed to the third main component of powerlessness and/or helplessness, namely the next of kin's feeling of insufficiency. The feeling of insufficiency contained an assumption/wish of wanting to be sufficient, take part, and act in relation to the patient's situation. The insufficiency concerned the lack of resources, e.g. own competence and power, to relieve the patient's suffering, to stop the deterioration of the disease or to cause outer resources (such as the health care staff) to act. Feeling insufficient involved an unwanted feeling of passivity, and the consequence was dependence on external resources. Triggering included transitions when the patient's health deteriorated and lack of symptom control.

"Powerlessness and helplessness have not been dependent on APHC. They really do whatever they can. What is difficult is to know what to do to help the sick person. I know that APHC tries everything to make it easier, but I would like to do more to help. She often has difficulties with breathing and I find it tough to hear how difficult it is for her". (The 54-year-old sister of a patient with uterus cancer.)

> After the operation I was told that it was incurable (the doctor's words). I, who all my life—I am 75—have been used to organising and deciding everything together with my family about our lives, I was suddenly totally helpless. I was seized with deep powerlessness when I understood that I couldn't do anything to help my wife. I thought I lost my foothold in life and I also got mental health problems with different false notions. . . . When I was deepest down in my depression I considered taking my life but my children and grandchildren held me back. . . . Perhaps the medical service should have offered psychiatric care or some other help more firmly. . . . I said 'no thanks' out of sheer downheartedness.
>
> (The husband of a patient with pancreatic cancer.)

Reactions to and deeper meaning of powerlessness and helplessness

Next of kins' reactions to powerlessness and helplessness included both physical and psychological symptoms, such as muscle tension, headache, loss of appetite, sleeplessness, anxiety/worry and depression. In addition, perception of patient's suffering and fading away and the feeling of insufficiency contributed also with a deeper meaning to the next of kin, including existential and social aspects, that was expressed as his or her own feeling of loneliness, guilt and anger.

Loneliness had a temporal dimension and concerned loneliness in the here and now as well as threat of loneliness in the future. Next of kin felt lonely when taking the practical responsibility and caring for the patient in the burdening situation. Moreover, being the only one seeing the patient's deepest needs added to a feeling of isolation.

Anger was directed towards the disease itself and the health care staff, the latter aspects involving delayed diagnosis and difficulties of getting help. Guilt was related to a feeling of not having done enough to relieve the patient's suffering.

The next quotation describes the existential feeling of isolation in a critical situation, despite social contacts, e.g. with children.

"It was like being alone in the whole world, you had nobody to talk to although you have children and grandchildren. I did my damnedest to help my husband and I think I did and it has helped me now afterwards that I know I did everything that was in my power to do. No, APHC and the medical service did what they could". (The wife of a 76-year-old patient with prostate cancer that had been cared for by APHC.)

Discussion

Although powerlessness and helplessness have been very little studied so far, the present study suggested it to be quite common among next of kin in palliative home care, with over 1/3 of the next of kin stating that they experienced powerlessness and/or helplessness during palliative home care. The present study also contributed with a draft of what characterises situations where next of kin feel powerlessness or helplessness and the meaning of such feelings to next of kin. The findings involved different abstraction levels, ranging from perception concerning the patient's situation to deeper existential meanings, namely: (1) next of kin's perception of patient's suffering, (2) perception of patient's fading away,(3) next of kin's feeling of insufficiency and (4) reactions to and a deeper meaning level involving existential and social aspects, with feelings of guilt, anger and loneliness. The main findings are supported by other studies in a palliative care context and by general literature about humans dealing with burdening situations [6, 12, 34, 38, 46, 48, 84]. In addition, the present study revealed aspects that seem important for the clinical situation but have not been much illuminated in earlier palliative literature, and therefore will be discussed below.

Next of kin's perception of suffering and traditional symptom control

The present study showed that the next of kin's experiences of powerlessness and helplessness were connected with their perception of the patient's suffering, e.g. pain. Previous research has shown that caregivers' experiences of powerlessness and helplessness are related to their perception of the patient's suffering of pain [17, 51, 83]. However, according to our findings, other aspects of a patient's suffering, such as nausea and breathlessness, also seem to have the same potential to elicit such feelings in next of kin. Research literature supports such findings, that is, that the family's and the patient's well-being are interrelated. For example, the patient's pain and anxiety can have a profound negative effect also on the next of kin [16, 31]. This is in accordance with the World Health Organisation's (WHO's) definition of the family as the unit of palliative care [80]: relief of a patient's suffering is considered as a way to promote next of kin's situation.

The present study highlighted also symptoms other than the traditional physical and psychological ones, such as pain and anxiety, that can contribute to next of kin's experience of powerlessness or helplessness, such as patient's loss of autonomy, basic functional activities and existential concerns. The dominant paradigm within Western health care, that is the biomedical model, has difficulties in responding to such psychological and existential suffering [37, 36], and the significance of these dimensions in palliative care has already been underlined by others, although not in relation to powerlessness and helplessness [5, 6, 39, 47].

The ability for practitioners to respond to various dimensions of suffering is dependent on the identification of different kinds of suffering. The findings stress the need for extending the traditional symptom control to also include existential and spiritual issues [5].

Next of kin's perception of patient's fading away and communication of awareness

Research has shown that a relative's awareness of the cancer patient's impending death usually progresses during the final 2 months of the patient's life [30]. Although awareness has been previously studied, there is little literature concerning what actually makes the next of kin aware besides the impact of explicit, open information from the health care staff [25, 62, 67, 68, 74], and also how next of kin signal their perception of the patient's fading away to health care staff [12, 30, 85].

This study showed that alterations in the patient's body and its functions, like strength, contributed to next of kin's experience of powerlessness and/or helplessness. This is supported by the study of Davies et al., which showed that decline in the patient's physical condition was a signal to the families that the end was approaching [12]. In addition, the findings of this study illuminated that changes in the person's individuality, e.g. from being an alert person with strong wishes to one who was no longer able to express her/his own needs, could also elicit such awareness. The mechanism was that when next of kin perceived changed attributes of the patient and his/her situation, such symbols or clues made the next of kin realise the progress in the patient's deterioration.

There has been little discussion of symbols or cues within the palliative context, although there is clear support for the general idea in relation to death and dying and communication between patients, next of kin and palliative care staff [12, 22, 47, 66]. Effective communication can play an important part in facilitating an adaptation in threatening situations, such as becoming aware of a relative's or friend's approaching death [2, 15, 33, 35]. Therefore, it seems important that staff communicating such matters has an understanding of non-verbal implicit clues and of their relevance and power associated to next of kin's awareness of patient's approaching death.

In the written responses, relatively few next of kin actually mentioned the words death or dying despite the fact that the study population consisted of both those next of kin of patients under on-going palliative care and bereaved ones (3–9 months after the patient's death). Instead, they used metaphors, such as fading away and being eaten up, to communicate their experiences. This way of being implicit relates to the findings of Salander and Spetz in their study of how couples deal with the threat of progressive malignancy. They showed that only few couples openly discussed death and dying. Instead, a mutual acknowledgement of the serious facts without using the words death and dying was more common and apparently sufficient [62]. The findings of the present study relate also to the concept of "middle knowledge" by Weissman, which he describes as "a mixture between awareness, acceptance and denial" [78], that is, knowing and not knowing (about serious illness) at the same time.

How can we understand this lack of explicit verbalisation? A means of controlling the level of awareness might be not to talk about the situation, because talking, more than thinking, implies emotionally confronting the unpleasant fact, a finding that is also supported by others [19]. This may also be the case concerning writing, as was indicated by our findings. In addition, lack of explicit verbal communication can also be a way of transforming difficult issues, e.g. death anxiety, into more manageable ones [84].

Next of kin's feeling of insufficiency and of deeper meaning and humans' search for action

The responding next of kin in this study described how the perception of the patient's suffering and fading away contributed to a strong and deep feeling of insufficiency and also existential issues, such as guilt, and this is supported by previous literature [46, 72]. The feeling of insufficiency implies an assumption that one wants to be sufficient, i.e. changing the negative process by action [65], and this seems to be a strong wish in the next of kin in palliative home care. The findings stress the significance of action and the importance of recognition of a deeper existential meaning level. This relates to the concepts "to do" and "to be", as suggested by Andershed and Ternestedt when they developed a theoretical understanding of family members' involvement in palliative care [1]. "To be" concerned the relatives' presence with the patient by being with him/her or by being in his/her world. "To do" was task-centred, and included relatives carrying out action or tasks related to a dying family member.

Victor Frankl stressed that humans are meaning-seeking creatures; however, it seems that the drive for action is also strong [21]. Such action needs of next of kin seem important to meet in palliative care.

Reflections

Should there be a treatment or therapeutic health care response for every condition in life, including powerlessness and helplessness, for example, when a dear friend or family member is dying? Is that not just life? Of course, no one can rescue a person from every experience of powerlessness or helplessness, but the problem is that if practitioners do not identify such common and burdening conditions, they will miss opportunities to provide adequate support.

The main findings provide tools for the practitioner to identify situations contributing to the next of kin's sense of powerlessness and helplessness. In addition, knowledge about the next of kin's feeling of insufficiency and deeper existential issues brings attention to the palliative care practitioners' important task in re-defining goals together with the patients and their next of kin, inviting the next of kin to participate in the care when and to the extent they so wish. It seems important to further study what facilitates and what impairs the next of kin's sense of powerlessness and helplessness.

Methodological considerations

The frequencies should not be seen as the "true" prevalence of how many next of kin have experienced powerlessness and helplessness during APHC because of the risk of recall bias in the bereaved group and the "contamination" from experiences at times other than during APHC. However, even knowing this risk, we wanted to include the bereaved group anyway to contribute with variations of the phenomenon, because time can re-frame and give distance to the experience. Moreover, the questionnaire has not been tested for test-retest reliability, criteria and construct validity, for reasons described in the "Patients and methods" section.

Acknowledgements We thank the staff at the APHC teams in Östergötland for various kinds of help, Monica Ulriksson for typing the responses, and the Swedish Cancer Society and the County Council of Östergötland (The Committee for Medical Research and Development) for financial support.

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