

Dying cancer patients' experiences of powerlessness and helplessness

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Abstract

Goals of work Experiences of powerlessness and helplessness are closely linked to incurable diseases but seldom studied in patients with disseminated cancer. The aim is to explore the perception, experiences and significance of powerlessness and helplessness, to study triggering factors and to make quantifications.

Materials and methods One hundred three patients, enrolled in four different palliative home-care settings, completed a questionnaire with both Likert-type questions and open-ended questions. The response rate was 58%, and background data was reported as frequencies, whereas the main material was analysed using a qualitative content analysis.

Main results Impending death, symptoms, loss of control and autonomy, ignorance, isolation and uncertainty constituted the basis for powerlessness and helplessness, but each factor was reinforced by the occurrence of suddenness, high

intensity and/or lengthiness. In total, 65% reported definite experiences of powerlessness and helplessness. These feelings also held a deeper meaning, involving aspects such as existential loneliness and hopelessness. They were ultimately caused by an incapacity to control feelings and cope with the situation related to the impending death. The results are discussed in relation to Cassel's theory of suffering and existential psychology.

Keywords Powerlessness · Helplessness · Palliative care · Existential · Cancer

Introduction

A recent study showed that powerlessness and helplessness are issues of clinical significance to family members in palliative care [1]. A third of the family members of cancer patients' families in advanced palliative home care stated that they had experienced powerlessness or helplessness every day or several times a week during the period of the care [1]. They described powerlessness and helplessness as feelings of insufficiency that could result in both physical and psychosomatic symptoms such as muscle tension, headache, and loss of appetite, anxiety and depression. The experiences also included strong feelings of guilt, anger and loneliness. As the family members' feelings probably are reflecting the patients' situation, powerlessness and helplessness are expected but seldom studied problems in palliative home care, from the patients' point of view.

Etymologically [2], the original meaning of the word helplessness is inability to help oneself, whilst the meaning of powerlessness is related to inability to defend oneself. A literature search confirmed that both powerlessness and

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helplessness are relevant in relation to patients' experiences in the field of health care. Feelings of powerlessness, for example, have been described in relation to serious diseases [3–6] and suffering [7–9]. Patients' efforts to cope with perceived powerlessness have previously been described as "the essence of ill health" [10] and as a major demand throughout chronic illness [11]. Both powerlessness and helplessness have been associated with depression [12, 13], and helplessness has even been listed as a criterion for depression in terminally ill patients [14].

Prerequisites for effective coping are awareness of one's own resources and confidence in one's ability to take advantage of support available [15, 16]. In the theory of learned helplessness and depression, a core feature is perceived inability to handle a situation [13]. Poor copers usually feel powerless [17–19], and this has a big impact on their possibilities to handle crises during serious diseases.

Helplessness has been described as one of several core phenomena in demoralisation syndrome [20], a condition that comes from a persistent inability to cope. This syndrome is correlated to a wish for hastened death. Even Freud [21] related to helplessness as something that provoked agony. He stated that it was a feeling that signals a danger that is deemed unmanageable. Powerlessness is also discussed within existential psychology, as the existential demands when facing death may be insurmountable and may result in a deep sense of resignation [22–24].

Explicit studies of cancer patients are still mainly lacking. Bearing this in mind it appeared important to study experiences of powerlessness and helplessness in palliative-care patients. The overall aim of this study was therefore to illuminate the perceptions, experience and significance of powerlessness and helplessness in patients with an incurable cancer and enrolled in palliative home care, to explore factors that trigger the experiences and to make descriptive quantifications.

Materials and methods

Study population and setting

The study population was recruited from four palliative-care units in two different Swedish counties. The study design was cross-sectional and targeted adult, Swedish-speaking patients diagnosed with cancer. The four units were advanced palliative home-care teams (APHC), and they had a similar palliative care organisation in accordance with the Swedish model, with a multi-professional team including a physician, 24-h services and access to a backup ward [25].

During the study period, 236 cancer patients were cared for by the four units participating. Because of exclusion

criteria (cognitive failure, excessive weakness or language difficulties), 198 of 236 patients were eligible for the study. Moreover, 20 patients died between the first distribution of the questionnaire and the reminder. In total, 103 of these 178 patients that were available after one reminder responded (58%). Data was collected between May 2004 and February 2005.

The characteristics of the 103 respondents are presented in Table 1. Because the questionnaire was submitted anonymously, a formal analysis of the dropout rate was not possible, but there were no major differences between the respondents and non-respondents concerning gender ratio for three of the four units (respondents=42% men; study population=47% men) and median age (69 years; 66 years). Owing to failed administrative communication, data on age was not collected for non-respondents in one of the four units.

Data collection

A questionnaire was constructed by the authors. Content validity was checked by the staff (doctors; $n=4$), registered nurses ($n=3$) and one social worker, who were not

Table 1 Characteristics of the responding patients ($n=103$)

Characteristics	Value
Sex (male/female)	43/60
Age in years (median (range))	67 (40–91)
Married or cohabiting (n)	77
Living alone (n)	26
Origin of patients malignancy (n)	
Gastrointestinal	21
Genito-urinary	19
Lung	12
Breast	12
Gynaecological	8
Other or unknown	31
Time since diagnosis (n)	
0–3 months	5
3–12 months	31
>1 year	66
No response	1
Last week I	
Was confined to bed nearly all the time	15
Managed to stay up about half the day	19
Managed to stay up most of the day	62
No response	7
How do you think the APHC-team has served you so far?	
Very poorly	0
Fairly poorly	1
Acceptably	3
Fairly well	12
Very well	87

otherwise involved in the development of the questionnaire but were experienced in palliative care. Some of them were also researchers in the field of oncology and/or palliative care. The questionnaire was additionally distributed to five patients at individual meetings with the third author. This showed that the questionnaire was feasible, and only minor changes were made, mainly removal of ambiguous phrasing. Another pilot study was distributed to 63 patients. Based on this study, the exclusion criteria (as mentioned above) were set: cognitive failure/confusion, patient being too weak to participate (as assessed by staff member) or language difficulties. Thereafter, no further changes were made.

The final questionnaire had both a qualitative and a quantitative part. The rationale for combining both a qualitative and quantitative part was to capture the spectra of thinkable factors that could have an impact on helplessness and powerlessness as well as the informants' own view of the inquired experiences.

The minor quantitative part consisted of questions concerning background data on the patient (e.g. age, gender, patient's diagnosis), his/her overall assessment of the support from APHC (five-grade Likert type; from 'Very bad' to 'Very good') and frequency of feelings of powerlessness and/or helplessness during the APHC period (five-grade Likert type; from 'every day' to 'never').

The qualitative part (the main focus of the questionnaire) consisted of open-ended questions asking the patients to describe in their own words their experiences of powerlessness and/or helplessness and to provide a concrete example of a typical situation.

The overall design of the open-ended questions was inspired by a qualitative interview technique whereby the informants are asked to share a concrete situation in which they have experienced the study phenomenon (in this study powerlessness and/or helplessness) [26] (p. 123). The patients' descriptions of their experiences were guided by open-ended questions such as "What do powerlessness and helplessness mean to you?"; "Would you like to describe a situation in which you have experienced powerlessness and/or helplessness?"; "How did you manage the situation?"; "Did it help?"; "Could healthcare have facilitated or prevented that situation?"; "In what way?" In addition, there were also some questions related to sources of strength and experiences of meaningfulness in the questionnaire. These data are reported separately.

The study was approved by the Regional Ethics Committee.

Analysis

The responses to the open-ended questions were analysed using qualitative content analysis with no preconceived

codes [27–29]. All the answers to the open-ended questions in the questionnaires were included in the analysis. The applicability of qualitative content analysis as a method of analysis of open-ended questions in questionnaires has been described previously [30].

The analysis was performed using the following steps. Firstly, all responses were read through to obtain a sense of the whole and to develop themes. Secondly, the responses were re-read systematically, line by line, to identify significant text segments, i.e. "meaning units," and to develop matching codes, preliminary categories. The actual words written by patients were used as far as possible. Thirdly, the statements in each preliminary category were scrutinised and compared to find their central component and were fused into categories. Fourthly, the final categories were compared to avoid obvious overlapping, and content descriptions and relationships with other categories were developed. To start with, the text material was analysed with a manifest focus, i.e. a descriptive analysis close to the text and the informants own choice of words [27, 28]. These results are presented as categories related to "Triggering factors" and "Aggravating circumstances." As the data were considered to be rich enough with several detailed stories of episodes, we extended the study by a qualitative content analysis with a latent focus, i.e. an interpretation of the underlying meaning of the text [27, 28]. These results are presented as categories related to Existential meaning. Quotations were used to exemplify the categories (Table 3). The responses to the quantitative part of the questionnaire were summarised with descriptive statistics (Table 2).

Trustworthiness

Coding and development of categories were mainly carried out by the first author, and the co-authors concentrated on the validation of the results. Involvement of several researchers is a way of reducing the risk of investigator bias, by researchers supplementing and contesting each others' readings, corresponding to reflexivity [31]. In addition, this study involved three researchers representing

Table 2 Patients' experience of powerlessness and/or helplessness during advanced palliative home care (APHC)

During the APHC I have experienced	Number	Percent
Everyday	5	5
Several times per week	10	11
Every month	14	15
Occasionally	31	34
Never	32	35
Not responding	11	–

Table 3 Overview of the qualitative categories that emerged in the analysis of the responses to the open-ended questions

Loss of control		
Triggering factors	Aggravating circumstances	Existential meaning
Serious information about the disease	Suddenness	Confrontation with a death threat
Symptoms	High intensity	Existential loneliness
Limitations		
Dependence	Lengthiness	Hopelessness
Being ignored		
Social loneliness		
Uncertainty		

different genders (male, $n=1$), professional backgrounds and preconceptions. To further strengthen the validity of the study, a peer debriefing was conducted, and the results were presented at two different research seminars involving clinically experienced nurses and social workers, Ph.D. students and senior palliative researchers.

Results

Sixteen percent stated that they had experienced powerlessness and helplessness everyday or several times per week, 49% stated that they had done so occasionally and 35% reported no experiences in the quantitative section (Table 2). However, in the open-ended responses, 8 of those 32 who indicated “never powerlessness” in the quantitative part still gave descriptions of situations related to powerlessness and their disseminated cancer.

In the questionnaire, the informants were requested to answer the question “What do powerlessness and helplessness mean to you?” Many of them said that the words were difficult to separate and that they considered the meaning of the two words to be overlapping.

The analysis generated categories that are presented under the headings Triggering factors, Aggravating circumstances and Existential meaning (Fig. 1). Those were all aspects that were related to the informant’s loss of control. An overview of the categories is presented in Table 3.

Triggering factors (manifest, descriptive focus)

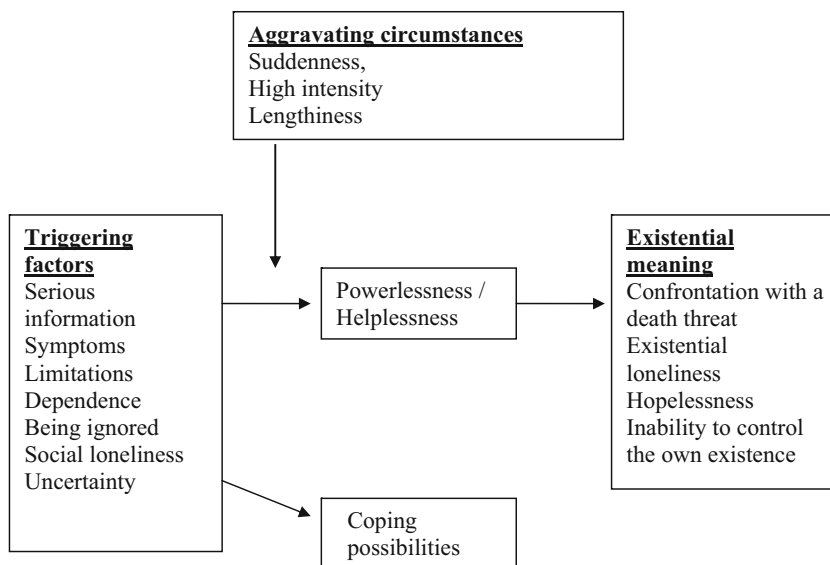
Serious information about the disease

When the cancer first was diagnosed, the message had affected one’s whole existence and turned the world upside down. The information about the fact that the disease was beyond cure and was in a late palliative stage had brought about insight about dramatically shortened life and impending death, which resulted in a loss of energy and feelings of both powerlessness and helplessness.

[I had a] traumatic reception at the hospital. First [I heard] ‘fatal disease, then ‘perhaps operable’ but ‘the most complicated one we do here’. Such information creates anxiety, worry and feelings of helplessness. Then ‘you’ll maybe live until Easter without an operation—powerlessness. (Married man, 82 years, gastrointestinal cancer)

However, it was not only the transition to a palliative phase that was of importance but also the occurrence of

Fig. 1 Triggering factors and aggravation circumstances, causing experiences of powerlessness and helplessness



certain factors and situations such as symptoms, limitations, dependence, social loneliness and uncertainty.

Symptoms

The patients described a variety of symptoms and problems that brought about powerlessness and helplessness. Prominent problems mentioned were pain, dyspnoea, nausea, fatigue, urinary and faecal incontinence, sleeplessness, anxiety, cramps and fainting fits as well as intimate handicaps such as sexual problems in younger patients

[I feel helplessness and powerlessness due to] Lack of energy, problems with my stomach, sex doesn't work (Married man, 50 years, gastrointestinal cancer)

Limitations

The disease had resulted in psychological and even existential limitations, related to the disease itself or to treatment side effects. Bodily functions were affected, as was also spirit. For example, fatigue prevented the informants from keeping on doing the familiar everyday things that they wanted to do, and this reminded them of their fragile situation and impending death. These frustrating restrictions had made the informants feel unable to control their own existence practically and economically, and these were also burden restrictions on their loved ones.

“Maybe not having time or energy to phase down my life, make my will, cleaning up all the stuff you save, etc, etc”... “not being able to take care of one's pets.” [these things create a feeling of helplessness and powerlessness in my life] (Man, 63 years, living alone, prostate cancer, able to stay up most of the day)

Dependence

The cancer progression increased dependence on others in everyday life. Receiving the necessary help—even in the most private and intimate situations such as visiting the toilet or for personal hygiene—from persons you did not know at all resulted in feelings of powerlessness. The informants also described feelings of powerlessness in their dependence on the health care systems' administrative and bureaucratic struggles

I can be powerless in relation to health care and home care systems, when others are setting the roles. (Woman, 73 years with breast cancer)

Being ignored

Some of the patients felt that ignorant behaviour had caused delayed diagnosis and treatment. This caused a feeling of

powerlessness. It also emanated from situations of being ignored or treated as a non-existent person. As one patient put it:

When someone is talking over my head. (Married man, 83 years, bedridden)

Social loneliness

Involuntary social loneliness was a factor that contributed to feelings of powerlessness and helplessness. The informants wrote about a shrinking circle of acquaintances. People ceased to call and this resulted in feelings of being forgotten. Sometimes, poor family relationships prevented them from meeting those they missed the most, e.g. their own children. Troublesome and embarrassing symptoms could be another hindrance in meeting other people.

The fact that the stoma doesn't work. All the discharge from my bowels. The fact that I can't move without knowing where the nearest toilet is. [due to this I]“can't go to organised activities or meet my friends. (Married man, 84 years)

Uncertainty

Living with a feeling that anything could happen at anytime and living without normal time references was experienced as being most frustrating. There was nothing to relate to, act in accordance with or react to—nothing to brace yourself against.

Uncertainty had obtained through all the stages of cancer. Was it cancer or not? Will the treatment work or not? Will there be a relapse or not? And finally, there is question about the survival time. The uncertainty made it difficult to make plans both for the day and for the longer term.

It's knowing that your doomed to death, but not how long you have to fight. (Married woman, 58 years, kidney cancer, bedridden)

Aggravating circumstances

During the course of analysis, three factors emerged, each one of them influencing the patients' experiences and the consequences of the triggering factors to a very high degree. These factors were suddenness, high intensity and lengthiness.

Suddenness, high intensity and lengthiness

Often, it was not the actual symptoms that were the main problem but rather the ways these symptoms presented

themselves. If they had appeared suddenly, were severe and prolonged or impossible to cure or explain, then they greatly contribute to the feelings of powerlessness and helplessness.

When the medications not are able to stop my pain
(Man, 54 years, lung cancer)

Besides the symptoms, unpleasant surprises were also described as being difficult to handle, e.g. receiving bad news about the disease, without being prepared or expecting such information, and this had psychologically affected the informants' whole existence.

I have always been a person with many irons in the fire. All of a sudden I am not capable to do anything. In that situation one is feeling totally helpless. (Married woman, 64 years, liver cancer)

Overnight everything was changed. (Woman, 61 years)

Another situation was having to deal with many different trials at the same time. Powerlessness was related to exhaustion in the thorough battle with the disease, a struggle with financial problems and worries about who is going to take care of all the stuff that will be left behind.

The Existential meaning (latent, interpretative focus)

Confrontation with a death threat

The primary cancer diagnosis had been perceived as a death sentence. One's own life was threatened, and the earlier existence did not rest on the same solid ground that had previously been taken for granted. This profound existential transformation was scary and difficult to cope with, but patients still tried to defend themselves against the insight about the seriousness of the disease and to maintain the control over the body and existence for as long as possible. When the cancer gradually worsened, the difficulty of keeping reality at a distance increased. It was impossible to hide from it all the time.

My brain isn't working right. You get wiped out for a while. You feel like your head's a sieve. Then you feel the powerlessness: is it ME who's sick? Why did this strike me? (Married woman, 61 years, gastrointestinal cancer, able to stay up most of the day)

Existential loneliness

Because of the symptoms and limitations brought about by the disease, the informants had been more and more dependent on others, a fundamental change that had been associated with considerable emotional efforts. They had

felt deserted and helpless in an unaccustomed way, and this provoked feelings that were extremely hard to handle. Seemingly, small everyday situations provoked deep existential insights.

I was going to put on panty hose and discover that it's a garment (it's made) for healthy women, not sick ones. Then I experienced a sense of impotence, powerlessness and helplessness. Death must come as a relief. (Married woman, 64 years, gastrointestinal cancer)

In such situations characterised by loss of control, altered self-image and a life threat, the informants talked about experiences of existential loneliness despite close family bonds. This was especially obvious when other people had been talking over their heads, as if they were non-existent or when they had perceived that their own situation was impossible to share or for others to really comprehend.

[It's so difficult] to make relatives and friends to understand the fact that one is sick when you have a disease that is not visible from without...One has a feeling of being forgotten. (Married woman, 76 years)

They described how discussions and questions related to the disease had gradually become more infrequent and had finally stopped. This had raised feelings of being an outcast.

Then it became quiet. [Other people seem to think] that this is like something from outer space." (Married woman, 51 years, breast cancer, able to stay up most of the day)

Hopelessness

Accordingly, the patients wrote about experiences of loss of control, their own inability, growing dependability and feelings of loneliness. They had to cope with the burden of uncertainty. When they looked into the future, there were no signs that gave them any hope of alleviation. The informants had perceived themselves as not being in charge of their own existence, and it was difficult for them to protect precious values and meet responsibilities, both socially and economically. These circumstances had resulted in experiences of lost human dignity and a threat to their self-image. The informants also described a point of no return.

Powerlessness: After a long life filled by work, there's no human dignity left. (Married woman, 83 years, bedridden)

When I feel powerlessness I see no possibility of doing anything. (Woman, 71 years, living alone)

Discussion

The informants experiences of their own inability to control the consequences of the disease are common to all the categories, in relation to triggering factors as well as aggravating circumstances and existential meaning. Human beings are vulnerable and only have limited resources to combat and control life-threatening distress. Being subjected to a death threat is one of the most challenging experiences of all, a truly existential borderline situation [24, 32] in which people really have a need for effective coping abilities. In this study, different circumstances had weakened or destroyed patient's coping ability. When they were unexpectedly confronted with suffering, they were poorly protected, resulting in experiences of both existential loneliness and hopelessness. This is in good agreement with the writings of the existential psychotherapist Yalom [24]: He writes "Occasionally some jolting experience in life tears a rent in the curtain of defenses and permits raw death anxiety to erupt into consciousness. Rapidly, however, the unconscious ego repairs the tear and conceals once again the nature of the anxiety" ([24], p. 44). With this approach, the capacity to "repair the tear," i.e. the ability to cope, is a prerequisite when it comes to the possibilities to managing life with an incurable disease. This knowledge has also been delivered by other researchers [11, 16, 18, 19].

The fact that the ability to cope is of outmost importance has also been stressed also in studies of demoralisation syndrome [20] and learned helplessness [13]. A core feature in both these conditions is people's perceived inability to cope with and control their own situation.

As mentioned before, suddenness, high intensity, lengthiness and uncertainty were four different characteristics that contributed very strongly to the informant's inability to cope. The fact that suddenness could be distressing in connection with information about a serious disease has been pointed out earlier [7, 33–35]. On the whole, suddenness in association with serious diseases is a factor that should be considered aggravating. It prevents people's organising new information in a way that makes it comprehensible for them and is also a obstacle to the psychosocial transition, a process necessary for the integrations of bodily and existential changes [36]. Therefore, literature on how to break bad news recommends "giving warning shots" [37, 38].

Uncertainty as a key factor is confirmed in other studies [9, 33] and is a crucial component of anxiety. Therefore, information, knowledge and awareness, even regarding a severe cancer diagnosis, are beneficial [39] as they relieve existential anxiety.

Hopelessness has been pointed out as being a strong predictor for desire for hastened death among terminally ill

cancer patients [40–42]. In our data, hopelessness was a consequence of progressive loss of anatomy, uncertainty and a perceived loss of dignity.

Our results can also be interpreted using Cassel's writings about suffering [7]. According to Cassel, suffering is experienced by persons, not merely by bodies, and has its roots in challenges that threaten the intactness of the person as a complex psychosocial and existential entity. It can arise in relation to all aspects of a person: social roles, group identification, the relationship with self, body, family or the relationship with a transpersonal, transcendent source of meaning and hope. In this study, the patients described different triggering factors that under certain circumstances provoked feelings they were unable to cope with. They were overwhelmed by thoughts and feelings connected with their own impending death.

The fact that the body, especially during severe illness, influences psychological and existential well-being is also in accordance with Merleau-Ponty's thoughts about the lived body [43]. We not only *have a* body, but in our existence we *are* bodies and bodily suffering induced by a disease affects both mind and soul.

Life crises and so called boundary situations are also highly relevant within existential psychology [22–24]. Confrontations with one's own impending death is an important experience that not only provokes anxiety but also elucidates different states of existence and offers a possibility of living in an authentic fashion. Although awareness of death can be meaningful in certain situations [44], it may also be overwhelming and may impair coping. In our data, aggravating circumstances such as suddenness, high intensity and long duration had contributed to this. It seems important to reduce the impact of both triggering factors and aggravating circumstances within palliative care, to facilitate the dying patient's ability to cope. When a situation can no longer be resolved, acceptance could be the least painful strategy, something that is stressed by many existential thinkers [24, 45, 46].

Methodological considerations

Every data collection method has its weaknesses as well as its strength [47]. Open-ended questionnaires are a supplementary data collection method that facilitates the revelation of more aspects of a phenomenon than frequency distribution of predetermined response variables can achieve. They can be generalised to a larger extent than interviews because of the larger possible numbers of informants, although the descriptions are less rich. Moreover, postal questionnaires may be better than interviews at enabling respondents to express dissatisfaction [48]. Thus, in this study, a combination of representative sampling with open-ended questions was chosen, giving

more than 100 dying individuals an opportunity to express their perspectives.

The reader should also be aware of that the majority ($n=99$ of 103) of the patients perceived that they had received good or very good support from the palliative-care service. These circumstances may have consequences for the transferability of the results to groups of palliative patients with more negative experience of palliative home care.

Implications

One way to relieve suffering is to prevent loss of control and facilitate coping. This could be done in different ways. Based on the findings from the current study and related literature, we suggest the following implications:

- Multi-professional work is important because contributions from different professions are valuable, e.g. physical symptom control, psycho-social counseling and soul care. An earlier study has shown the value of hospital chaplains involvement, regarding both religious concerns and general existential talks about meaning, death and dying, illness and relationships [49].
- Striving to provide serious information about the disease in gradual stages, to avoid uncertainty is of great importance [37, 38]. One example is to always give information about alterations and delays.
- Allowing patients to take active part in their own care and avoid taking over is one way to preserve their sense of intact autonomy [7].
- Of course, it is essential that the staff is available for questions and support. However, it is at least as important that they have the courage to be there even when there is nothing to be said [50].
- It is valuable to facilitate social contacts and the maintenance of important relations [51, 52]. Experience of existential loneliness as a basic given for all humans and therefore impossible to eliminate is described by both psychiatrists and philosophers [24, 46, 53]. It is known that when it is possible to relate to others, the perception of existential loneliness may decrease [24, 54], and it is important not to underestimate the value of human encounters.
- That hope is a core factor when it comes to humans ability to cope is a well-known fact [16, 55]. The current study shows that hope can be linked to so much more than a cure: being spared from painful symptoms, having the possibility of being taken care of in one's own home and experiencing death without severe

suffering [56]. The staff should therefore work with these sources of hope in mind.

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Questionnaire

(The questionnaire was delivered in Swedish. This translation is only approximate.)

Below follow some questions about yourself. Can you please put a cross in the corresponding square and write your answers on the lines.

My sex: Male Female

My age: _____

I live:

- Together with my husband/wife/cohab
- Together with another person (who not is my husband/wife/cohab)
- Alone

The recent week I:

- Was confined to bed nearly all the time
- Managed to stay up about half the day
- Managed to stay up most of the day

For how long have you been enrolled in APHC?

- Less than 1 month
- 1-3 months
- More than 3 months

Diagnosis?

If cancer, what kind? _____

If cancer, is it disseminated Yes No I do not know

For how long have you been aware of your disease?

- 0-3 months
- 3-12 months
- More than 1 year

How do you think that the health care has served you during this time?

- Very poorly
- Quite poorly
- Acceptably
- Fairly well
- Very well

How do you think the APHC-team has served you so far?

- Very poorly
- Quite poorly
- Acceptably
- Fairly well
- Very well

Here below follow some questions concerning your possible experiences of meaning and also of powerlessness or helplessness connected with the disease and need for support. Write as much as you desire, lengthy or short, all answers are valuable.

If you do not wish to describe your experiences we would still be grateful if you could mark on the last page whether you have had experiences of meaning, powerlessness or helplessness, respectively, during the time of the disease (questions 8-9). If the space for writing is too limited, please use another paper or write on the opposite side of the paper.

1. What creates meaning and what is important in your life?

2. Would you like to describe an event during your time of illness that was meaningful and important to you? You can describe more than one situation if you like to. We are especially interested in the period during which you have been enrolled in APHC.

3. Do you think that the health care system can facilitate/could have facilitated you feelings of meaningfulness?

4. What causes powerlessness or helplessness in your life?

5. Would you like to describe an event during your time of illness that resulted in feelings of powerlessness or helplessness? How did you try to cope with/solve the situation? Did you succeed? You can describe more than one situation if you like to. We are especially interested in the period during which you have been enrolled in APHC.

6. Do you think that the health care system could have done anything to prevent or lessen your feelings of powerlessness or helplessness? If yes, in what way? If no, why not?

7. You, who rarely or never have felt powerlessness or helplessness, what do you think have helped you to elude it?

8. During the period of care in the APHC I have experienced meaningfulness:

- Every day
 Several times per week
 Every month
 Occasionally
 Never

9. During the period of care in the APHC I have experienced powerlessness or helplessness:

- Every day
 Several times per week
 Every month
 Occasionally
 Never

Would you like to add anything else?

Thank you for your participation!

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