Existential Loneliness in a Palliative Home Care Setting

LISA SAND, M.S.W., and PETER STRANG, M.D., Ph.D.

ABSTRACT

Background: The diagnosis of an incurable disease implies an existential crisis. This study focused on the emotions, perceptions, and experiences of existential isolation in palliative patients with cancer and their families.

Materials and methods: A total of 40 respondents (20 patients and 20 family members) were interviewed in depth. All were Swedes who defined themselves as nonreligious. The patients were enrolled in an advanced hospital-based home care team. The interviews were taped, transcribed, and analyzed with a qualitative, hermeneutic method.

Results: The data revealed experiences of existential loneliness with the impending death as a primary source. Experiences of being alone in "a world of one's own" were common. The changes in everyday life and the increasingly restricted social interaction because of the illness meant that the patient partly lost the protection against isolation that the spirit of community normally provides. Other situations that had a triggered the existential isolation were, for example, when a patient in need of support was left alone, when he or she was treated disrespectfully or in a way that made him or her feel invisible, or when people avoided contact because of uneasiness or fear. Changes in one's own body and mood gave rise to feelings of loneliness and unfamiliarity toward oneself. When a staff member touched the patient's body in a nonempathic way, this could induce feelings of being treated like an animal.

INTRODUCTION

According to an existential psychological view, the diagnosis of an incurable disease always triggers a crisis reaction, both in the patient and the family. The great questions about life, meaning, responsibility, existential isolation, and death are suddenly part of everyday life. This type of crisis is normally labeled a psychological or traumatic crisis but ultimately it is a profound existential crisis, as the patient's life, as well as the everyday life and the future of the family members are threatened.

According to philosophers like Mijuskovic and Tillich, all living creatures are basically alone and isolated. To live is to exist in a body that is separated from everyone else's. Each person is unique and a total emotional community between two individuals can never fully be reached. Man is not only lonely, but he is also aware of this existential predicament. Existential isolation is a basic challenge. This experience of loneliness is on one level shared by everyone. Experience of loneliness is also a driving force that makes us search for company and create relationships.

Solitude that is actively chosen can be positive and fill an important function. Involuntary isolation, however, is very different from this. In such instances one is thrown upon one's own re-

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sources, despite a strong will to be with others.\(^9\) Such loneliness is negative and associated with an experience of forlornness.\(^8\) Involuntary loneliness is also something that is linked to guilt and social failure.\(^10\) Such experiences are therefore something one wants to hide from others. Incurable diseases often activate feelings of involuntary loneliness, or at least fear of loneliness.\(^9,11–15\)

In the psychological literature from Western societies there are different definitions of loneliness and varying opinions of the cause of loneliness. However, many scientists agree on a definition that divides loneliness in three categories: interpersonal (social), intrapersonal, and existential loneliness.\(^1,16\) The borderlines are neither sharp nor absolute. The three forms of loneliness are intertwined and affect each other.

Several authors state that the experiences of loneliness are closely related to death and are one of the factors that make dying distressing.\(^12,15,17–20\) Death is designated as the occurrence that more than anything else symbolizes man’s profound loneliness and the inevitable separation and isolation from others\(^8,13\) and the one event when existential loneliness is most evident.\(^6\)

Despite the fact that loneliness has been investigated by researchers in different branches of science, to our knowledge, the existential isolation experienced in association with an incurable disease has not yet been systematically studied. Therefore, the aim of this study was to explore this experience of isolation, the origin of these feelings, and their interaction.

**MATERIALS AND METHODS**

**Setting**

The study was conducted in a Swedish palliative hospital-based home care service, with a capacity of 80 patients in their own homes on a 24-hour basis, run by a multiprofessional team.

**Patients**

All patients had a diagnosis of cancer, either in an early or a late palliative phase. The study comprised 40 respondents (20 patients and 20 family members). They were all Swedes and defined themselves as nonreligious. Data were collected with maximum variation sampling aiming at capturing and describing central themes that cut across variations\(^22\) because the perception of existential loneliness may vary in different groups. It was considered important for the study that variation was based on gender, age, family situation, occupation, diagnosis, total time of illness, and the phase of illness. Twelve of the patients were women and 8 were men. The mean age was 63 and the range was 21 to 91 years of age. The diagnoses varied, as did the time of diagnosed illness. Among the next of kin, 12 were spouses or cohabitants, the other 8 were children, parents, or siblings. Both the patients and their families represented a range of occupations (Table 1).

**Data collection**

The Ethical Committee at Karolinska University Hospital approved the study. A semistructured interview guide (Appendix A) with focus on open-ended questions was constructed by the two authors and discussed with colleagues in the multi professional palliative home care team. The interview guide should be seen as an aid for the interviewer,\(^22\) as a structure on which to hold on. A pilot study of two patients and two family members was conducted in order to optimize the

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<th>Table 1. Patient Characteristics</th>
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<tr>
<td>Demographic data</td>
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<tr>
<td>Total number of patients</td>
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<td>Gender (male/female)</td>
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<td>70–89</td>
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<td>Marital status</td>
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<td>Married/cohabitants</td>
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<td>Single/widow/widower</td>
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<tr>
<td>Professions</td>
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<tr>
<td>Blue-collar workers</td>
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<td>Civil servants</td>
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<td>Self-employment</td>
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<tr>
<td>Other</td>
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<td>Primary malignancy</td>
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<td>Urologic</td>
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<td>Gastrointestinal</td>
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<td>Hematologic</td>
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<td>Breast</td>
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<td>Brain</td>
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<td>Gynecological</td>
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<tr>
<td>Time from interview to death/months</td>
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<td>4–6</td>
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<td>7–9</td>
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questionnaire. Based on these interviews some linguistic adjustments were made to make the questionnaire more comprehensible.

The respondents were contacted by a telephone call from the first author; afterwards a formal information letter was sent. This contact either resulted in a decline to participate, a positive response, or a request for further information. If further information was requested the person could choose to receive the information by telephone or during a personal meeting with the interviewer.

The first author interviewed the informants on one occasion. The same questions were posed to the patients and family members. Depending on the response, further questions were posed, in order to explore, deepen, and validate the answers. The interviews lasted between 45 and 105 minutes and were tape-recorded and transcribed verbatim, mainly by the first author.

**Theoretical Framework and Analysis.** Data were analyzed by the two authors (a social worker and a consultant in palliative medicine and researcher with long experience in qualitative methods). Both authors have long clinical experience as palliative care specialists.

Interpretation was based on existential psychological theory. In existential psychology a person’s own subjective experiences are central. Investigation focuses on how he or she relates to basic existential questions about life and death, togetherness and isolation, meaning and emptiness, freedom, and external structure.

Data were analyzed by using existential hermeneutics. When choosing a hermeneutic approach, the aim is to get a deeper understanding of the expressed meaning and implicit issues and to elucidate the autonomous meaning of the text. It was important to choose a method that offered opportunities for interpretation, since the interviews concerned questions about death and dying, topics where there are good reasons to assume that the informant would not give explicit expressions due to fear or defense mechanisms. In this study the analysis has followed and considered seven principles for hermeneutical interpretation, as described by Radnitzky and adapted and extended by Kvale. These principles are: (1) continuous back and forth process between the parts and the whole; (2) interpretation ends when a good gestalt is reached, an inner unity of the text, free from logical contradictions; (3) testing the partial interpretations against the global meaning of the text; (4) autonomy of the text, i.e., the text should also be understood on the basis of its own frame of reference; (5) gernemeutical explication of a text concerns knowledge about the theme of the text; (6) an interpretation of a text is not presuppositionless; and (7) every interpretation involves innovation and creativity. This method has previously been used for similar research questions by our group and is presented in detail elsewhere.

In short, the analysis was performed in the following steps: The transcribed interview was at first read through without presumptions (naive reading) in order to gain a general picture of the content. In a second, more careful reading, meaning bearing units were coded preliminarily. In the next step these units were scrutinized, this time with focus on the potential underlying meaning. In this phase of the analysis it was possible to distinguish themes. When needed, extensive parts of the transcriptions were condensed and in order to focus on the core information and to illuminate this, the text was abstracted. Alternative interpretations were tested and compared, by means of juxtapositioning. The most plausible inherent meaning (when studying the parts) was then compared to the entire text (the whole) in order
to test the interpretation. This procedure, of comparing the parts with the whole was repeated several times, according to the hermeneutic spiral. The analysis was ended and the categories were labeled when the interpretation seemed coherent without logical contradictions. This is, normally referred to as a “good gestalt” in hermeneutic analysis.

The results are presented both in the form of parts (categories) and as “a whole,” where the whole represents a synthesis of the categories.

**Trustworthiness**

During the interviews a dialogical validation was performed. Similar questions were posed in different situations, in order to be sure that the informant’s view was captured in a reasonable way. Furthermore, dialogical intersubjectivity was the goal, meaning that both authors analyzed the interviews separately and compared their findings. In case of discrepancy these were discussed and common descriptions were formulated. The aim of the discussions was not to reach consensus, but to find possible alternative interpretations.

**RESULTS**

As a central finding, both patients and family members stressed how a profound experience of existential loneliness was founded in certain changes and circumstances during the disease trajectory. The changes that had lessened their ability to protect themselves against involuntary thoughts and feelings related to the impending death. This made people less prepared and more vulnerable when confronted with the impending death in a direct or indirect way. In certain circumstances this vulnerability became tangible (Table 2).

**Parts**

**Changes—Reduced Protection**

**Changed life conditions—changed existential protection.** The reality of the illness had transmuted death from something abstract concerning others, to something real, concrete, and highly relevant. Both patients and next-of-kin experienced that they now had thoughts and feelings impossible for others to really comprehend. Another consequence was that the family members no longer shared the same future or long-term life plans. Thus, plans related to family life, in some cases educational plans, career, grandchildren, or retirement had to be abandoned.

But I don’t want to survive and get a life that is nothing. Forced to be put aside, watching others who are capable of real life, do you understand what I mean? . . . No, I want to participate! . . . But what is going to happen, are the others going to continue without me? What is going on? . . . I feel that I still have so much left! 12a

**Altered everyday circumstances—loss of everyday protection.** Some of the external togetherness with others that was previously evident ceased to exist, both for the patients and the family members. They did not have the strength to socialize with friends or participate in leisure activities in the same way as previously. For the patient, even the inner sense of togetherness in the family was affected as routines were changed and family roles were shifted.

When the opportunities for togetherness decreased, the possibilities to seek protection in social company were reduced, leading to unwanted reminders of one’s existential loneliness and fear of death. This created an urge to meet family and friends and a need to see everyday life going on.

I haven’t been out for a long while and I haven’t seen real life . . . I know, it’s terrible but that’s the way it is. It is like I’m drifting

**Table 2. The Parts (subcategories) identified through the hermeneutic analysis**

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<thead>
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<th>Changes</th>
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<tr>
<td>Changed life conditions</td>
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<td>Altered everyday circumstances</td>
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<tr>
<td>Emotional changes</td>
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<td>The pathological changes of the patient’s body</td>
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<th>Circumstances</th>
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<tr>
<td>Not enough time</td>
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<tr>
<td>Ignored</td>
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<tr>
<td>Inability to communicate</td>
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<tr>
<td>Without information</td>
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<tr>
<td>Suffering</td>
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<td>Separate ways</td>
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<td>The next of kin’s experiences of responsibility</td>
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A synthesis of these parts forms the integrated “whole,” in agreement with the hermeneutic circle. The synthesis of the parts (“as a whole”) is presented at the end of the Results section.
away from life and in that way I have no protection from it (life) when I feel my anxiety coming.

Do you think this anxiety is related to thoughts about death?
Yes I think so, or for my own part I know that it is so. Death and loneliness are in a way associated. Maybe one is scared of death, just because one is afraid that death will mean that you will become totally alone.

19a

Emotional changes—one's own and other's. Both patients and next-of-kin described feelings that were no longer familiar to them. Some informants also described an existence with an altered energy of life, which could cause feelings of lost control. Sometimes the changes were great and really noticeable.

From “I considered myself as calm . . . I guess I was . . . an ordinary person” to “my temper is a disaster” and “the best thing for me is to be dead” [5a] is one example when the changes were so profound that it was difficult to cope with the situation, both for the patient and for others.

The pathologic changes of the body—unfamiliar and frightening for all involved. Patients could experience that their own bodies, which they earlier had relied on, now began to fail and former bodily power had been swept away. Such changes had also affected the next-of-kin both emotionally and practically. Treatments with severe side effects and operations had sometimes injured the body in such a way that the patient’s relationship to it had partly changed from familiarity to unfamiliarity.

Being aware of something inside one’s own body that was growing without control and creating feelings of repulsion could result in the perception of powerlessness and estrangement.

And it’s not as when you have a cold that disappears, it is here to stay for ever . . . will always be there. It feels scary, I think, like a monster that is inside of me. And then I can feel an even stronger urge to go training in order to curse (and challenge) this misery 2a

Symptoms from the body that were experienced as embarrassing could lead to withdrawal from other people. Not being able to eat and drink as before had a great impact on the social togetherness surrounding meals. This affected the whole family. In cases in which the patient tried to overcome the embarrassment and decided to see friends anyhow, the effort sometimes resulted in feelings of being cut off from former togetherness and in feelings of isolation that in a reality were impossible for others to really understand. One concrete example follows. One of the patients went out with his old friends as he had done several times before, but this time he wore diapers and he no longer felt part of the circle of friends.

If the bodily and emotional changes were very obvious and profound, this could result in experiences of being restricted, without the possibility of reaching out to others. It was impossible to find protection from feelings about the impending death, not inside oneself nor among others. One was confronted with thorough feelings of existential loneliness. One of the patients said,

Have you told anyone that you are afraid of being alone? No, no that would not be possible . . .

Why not?

It’s so unlike me . . . it’s fully enough with all the other changes (shows with a gesture over his body)

Is there anything else that you think about on your own?

I don’t know really . . . well it is about this fact that I’m going to die, that is difficult to talk about with those who are healthy, they are not in my position . . . They are thinking about other things 4a

Circumstances—Exposed Vulnerability

Not enough time—thrown into loneliness. The patients had experienced it both difficult and distressing when they were informed and abruptly confronted with something that could turn end their lives. Unable to adapt emotionally, they felt defenceless and thrown into loneliness.

Before the first operation, my brothers and sisters were very worried, but not me, I was as cool as a cucumber and I was sure that I could handle it all, but the second time . . . !
Why do you think it was so distressing the second time?

I was not prepared at all, no one had mentioned a thing, everything was in peace and happiness and (the tumour) only 12 mm, so tiny and then: bang! (the patient got a message by telephone about the tumour being much bigger) . . . it was a shock, a horrid shock! And into the hospital one day for cutting it away and then home the next day . . . awful! 1a

Ignored—do I still exist? In one’s own experiences were ignored by others as non existent, or met with unrealistic comments about recovering and a healthy future, it was perceived as a confirmation of the fact that one’s own situation was impossible to share with others or to really comprehend.

No, you must joke a bit like that, and when I do so, it won’t be that painful for the others . . . // . . . But only few people dare (speak about Death). My sister-in-law doesn’t dare “You will get well!” she exclaims. Then I say slowly, “I have a fatal, chronic disease.” Then she becomes silent and so we talk about things. 2a

The reactions of those around one lead to difficult thoughts and feelings related to the impending death being kept to oneself. Profound parts of one’s own existence were camouflaged. When one had been treated without respect or if one’s body had been touched without empathy, sensitivity and attendance, feelings of isolation and loneliness emerged. To be touched by “speedy hands, impatient hands” or hands that “hasten to get ready” are examples of that. Situations where the informants had felt like animals were described.

A woman with breast cancer who had had her breast removed related that during the visit by the surgeon he touched and expressed himself in a way that made her feel like a pig.

And when he was to operate on me, he came in and drew on my breast, he lifted it up like this, as it was something, well I don’t know what and then he said, “Well, this heavy hanging thing, you don’t need anyhow, do you?” . . . oh, what a horrid doctor!

Well . . .

But then after all, he came the following day to discharge me, but then I said, “Don’t you understand,” I said, “don’t you understand that I am maimed!” They had to take away quite a lot from my left breast too, namely, so that it wouldn’t cause undue extra strain.

I see . . .

It must be in some case sheet telling what his name was, that doctor, because I don’t remember that, but he was so disgusting . . . anti-women! He stood there, drawing on my body as if I were a bloody pig that he should carve. 1a

When others were talking above one’s head it provoked feelings of separation. One experienced less worth and that one was treated as an object. Sometimes one even felt invisible. One’s own conception of oneself did not fit any longer.

Inability to communicate—lonely for everyone.

The experiences of existential loneliness were often related to difficulties communicating feelings and experiences of the disease and the impending death, due to lack of practice, but also to show mutual respect. This was primarily described by the patients but also by the next-of-kin. The mutual respect was founded in empathic feelings but could nevertheless result in feelings of loneliness. A husband described his decision not to talk to his wife about the seriousness of the disease:

No, that I don’t want! . . . I think that . . . that will burden her, even more, eh? . . .

Well, . . .

But, but (sobs) I have said (cries, looks helpless and appealing) that we will fix this, haven’t I? . . . and . . . I will not change that 12b

While the patient described the situation in this way,

Is this something you can talk about?

No, because then he gets angry.

The part about you finding it all confusing now?

Yes, “You are not going to die, nonsense!,” says he. He can’t stand me being the least doubtful or like this: “Don’t talk like that!,” he just says then. 12a
The patients who were most severely ill were those who talked most freely about their existential loneliness. Their narrations portray a situation where they stepped towards a growing sense of existential loneliness. They described their fear of suffering and of going through agonies all by themselves and also verbalized their difficulties in coping with the fact that they were going to die alone. Thoughts and feelings about their own death were considered something impossible to share with others. Their unique experiences, made them feel retired from other people and isolated.

I wonder, what is happening when you die? Is it one moment like this and suddenly you are gone? I think that if I can sit here and fall asleep, what would the difference be between that and if I were to go into a coma . . . ? Just sit here and suddenly stop existing . . .

Are you afraid of that?
Yes, I am afraid of that situation . . . (long pause) . . . And being alone here at home. I don’t want to just sit here and deteriorate and struggle and experience a hard time all alone. 4a

Without information—out of control. If uninformed about details of the disease, different symptoms and side effects, both patients and next-of-kin could feel abandoned, since such information would have been useful when they were forced to cope with difficult situations at home. It was experienced as scary to be unprepared and in such a demanding situation.

And this is one thing I have thought about and we have discussed a lot, Linda and I: Why don’t they tell you? Is it because they are afraid of making you scared? Or because they don’t think it is important, or is it due to lack of time? Why don’t they tell you about what may and probably will happen?
You would have preferred to be informed?
Definitely! I don’t say that it would have been easy, but nothing has been easy. But with information we felt prepared and we knew what we had to deal with. Now we were put in a situation were we had no idea at all about what could probably happen. We were not prepared a single bit and how easy is that? 9b

Suffering—mutual existential loneliness. Patient suffering was a reminder of how life-threatening the disease really was: the lonely feelings that were provoked were considered something difficult to share with others. Both bodily and emotional suffering were described. Sometimes severe suffering could result in a desire to die, a desire difficult for others to understand and threatening for them even to hear about.

And I have told him (her son) that I must have permission to die when I’m not able to go on living any longer . . . I can’t go on for ever, I can’t stand the suffering.
And what did he say? Did you get his permission?
No, he didn’t want to (in a low and sad voice) 3a

Her desire to die made her impending death obvious to her family and confronted them with their own existential loneliness. Her husband said:

Actually, it was a period when she was on her way to giving up. She said that she could not manage things as they were then. That was when things were at their worst with the side effects.
Oh, I see . . .
But then I said, “You cannot give up now! You and I then! Think of your children, they have no dad, they only have me who is a surplus dad. And the grandchildren, think of them!” 3b

Next-of-kin were not responsible for the formal home care of the patients. Despite this, family members felt that they had to mitigate the patient’s suffering. When this was impossible they experienced that they were insufficient, powerless and lonely.

Because he threw up, as soon as he ate, he threw up. And I thought ‘What is to be the end of this?? What shall we do? 13b

Separate ways. The interviews, both with patients and next-of-kin, bear witness to an interplay between needs and the desires to talk freely
about the disease and death and to keep it all at a distance for as long as possible and hope for a long survival. However, as the disease worsened, the patient’s insight into their separate existences began to grow. The patients experienced symptoms in their own body, that resulted in earlier understanding of their condition: “The body is finished. It’s totally finished” [22a].

Next-of-kin stuck to frames of reference from healthy life for a longer period of the course of the illness. Step by step their former united lives separated and the patients started to finish their lives while the next-of-kin began psychological preparations for a changed but ongoing existence.

It is the same thing if Eva passes away. I might meet someone else. I might not move in with someone, that I don’t know, but I’ll not live by myself, that I won’t do. I must enjoy life and I want someone to love 3b

The predicament that the patient was soon going to die while the next-of-kin would go on living led to separate existential frames of references. In that sense, it was no longer possible to make plans for a future together.

Experiences of existential loneliness, that were described by the next-of-kin were often founded on the fact that they were going to be left alone. As long as the patient was alive they tried to keep this insight at a distance. Despite this, they sometimes got reminders of a future in loneliness and these reminders provoked strong feelings of sorrow, fear and desolation.

When the patient was a parent, the adult child described feelings of defencelessness and loneliness as if he or she were still a child: “My parents have always been there for me, but not any more” [9c].

In addition to this another existential predicament presented itself. Suddenly one was the oldest in the family and in that way one’s own death came closer: “Next time it could be me” [24c].

It All Depends on Me—Next of Kin’s Experiences of Responsibility. Next-of-kin described how they had carried a huge amount of responsibility, due to all the practical details surrounding the situation and the care for the patient.

I’m in suspense, yes, and I feel there is a fatigue all the time . . . You are in the front, all the time. 12b

It goes on without stopping! No, nobody can’t discern that! On and on without stopping—not a quiet hour? 21b

There had been a lot of administrative and bureaucratic struggles concerning important documents gone astray (e.g., information not reaching the x-ray department), telephone hours to wait for, doctors who did not call back and laboratory test results that were not reported.

It’s a frightful lot of minding. It takes quite a lot of time to check up on things, you know. First you have to take part in all these medical examinations, you see. Then you must keep a check on that we have been called, oh no, we haven’t, and why not, and then you call and say “But we should,” “Not at all! We have no referral,” “Well, but I know there is one,” you say then, “I was there when it was written.” “Well, it hasn’t turned up here yet.”

Well, then you call round to every possible place, and you know for sure when you call a hospital then it’s not a question of one single call. Four hours is nothing unusual until you get the answer you want! 9b

Several episodes of prolonged waiting time due to bureaucratic struggle had been experienced as very distressing. Because it all was about a loved one’s life-threatening disease, an existential dimension was added to the general irritation.

As a Whole

The Body—A Superior Category. Experiences of existential loneliness described by the respondents had their primary source in the knowledge about the impending death. The sick body became an alerting device that reminded all involved of the serious situation. The interviews, both with patients and next-of-kin, bear witness to a growing sensitivity in relation to the fragile body and an awareness of how important a healthy body really is, both in daily life and for their own identity. It was inside the patient’s body the disease had its seat and it was the body that produced signals interpreted as signs of improvement or deterioration. It was the condition of the body that determined whether one could take part or not in everyday life, as well as social
interferences and physical and emotional close-
ness. Therefore, the body came to be an impor-
tant factor concerning experiences of existential 
loneliness. Considering the state of the sick body, 
the families made plans for the day and the ac-
tual status of the body determined to what de-
gree the disease would influence the everyday 
life. Next-of-kin made their own interpretation of 
signs and symptoms from the patient’s body and 
depending on what they perceived they related 
to the situation in different ways (Fig. 1).

Despite the fact that the body usually is not 
looked upon as being an existential aspect, the 
emerged interview data that emerged stressed that 
human existence is ultimately based in the body.

**DISCUSSION**

Despite the fact that the informants were not ex-
plicitly asked about their perceptions of loneliness 
and that the words “lonely” or “loneliness” were 
not frequently used by them, it is obvious that ex-
periences of existential loneliness are common not 
only among the patients but also among next-of- 
kin. The explanations for this are varied.

Communicating loneliness is still difficult and 
something people hesitate to discuss because, at 
least in western societies, loneliness is a sign of fail-
ure and therefore suggests shame. The low sta-
tus of loneliness could contribute to making it a 
subject that is neither mentioned nor asked about.

The threatening dimension of existential lone-
liness also makes it difficult to talk about. It is 
closely related to death and one of the feelings 
that can evoke fear of death. Undisguised 
anxiety is a very painful experience that is hard 
to endure and therefore quickly overcome by de-
fece mechanisms. The raw fear of death is 
radioply transformed into a feeling less threaten-
and more possible to cope with.

The informants described how they had stress-
ful thoughts and feelings they wished to share 
with others but they found it impossible to do so. 
This is in good agreement with the writings of 
the Swedish tanatologist Loma Feigenberg. He 
describes how thoughts about the impending 
death dominate inside a patient with a life-threat-
ening disease, but what is noticeable of that from 
the outside is only a pale reflection.

Not all families talk in an open way about 
things concerning a life-threatening disease. Mu-
tual openness is not always easy and not 
always worth striving for. In the interviews the 
respondents expressed desires to protect their 
loved ones from thoughts and feelings that could 
be upsetting, which is a well-known phenome-
non. Therefore, some of them chose not to speak 
openly about the disease and the impending 
death. Sometimes the reason for not sharing feel-
ings was that the patient was convinced that 
healthy people were unable to understand and 
that it was useless even to try, an experience that 
has also been described in the literature previ-
ously.

Despite different, even good reasons to avoid 
talking about one’s own situation, communica-
tion is still an essential and important source of

![FIG. 1. Various changes and circumstances that were manifest or triggered by the bodily deterioration induced feelings of existential loneliness.](image-url)
the experience of affinity and togetherness. The desire to be seen, acknowledged and respected is a basic human need.

When Yalom writes about different forms of loneliness he stresses the lack of absolute boarders between them. On the contrary the borders are semipermeable. That means that they can both interact and masquerade. It is therefore plausible that the informants’ experiences of interpersonal (social), intrapersonal or existential loneliness were all transformed into a common experience of existential isolation that is the type of loneliness that is intimately intertwined with death. In this process the patient’s exposed body had a major significance.

Several researchers have described how significant the body is for the identity of a human being. Freud described the ego as being a “bodily ego” and according to Merleau-Ponty human beings both have and are a body. He states that the human subject, as well as her consciousness, are bodily based, and that she relates to himself or herself and others primarily through his or her body. As a result of this, changes in the body can influence a person’s whole identity and how she experiences and relates and thus a disease can give rise to experiences of unfamiliarity and homelessness. Still, none of these revisions developed their discussion further or included the body as a probable source of existential loneliness.

The results from this current study point out that this is the case, but it is important to emphasize that the results are valid for a severely ill body and that data cannot be directly transferred to other contexts. As a rule, a healthy body is possible to control directly and by mental power. It is possible to neglect small aches and pains and pull oneself together if the body is tired. However, if you are aware that you or a next-of-kin are seriously ill, and you develop symptoms that are strong reminders of the impending death, this is harder to manage. In such cases, symptoms and symptom relief are about life and death.

Sometimes the term “skin hunger” is used in descriptions of how important it is for the human body to be touched. When the hunger is not satisfied this could be called an “physical loneliness,” a term that is rarely used. When one has a body with transudations, discharges, and noises, one looks different, aches, and sometimes smells bad it can be difficult for all involved to meet and be intimate or even stay close. In the same way it may be difficult to cope with the fact that parts of the body are surgically removed or that new details such as subcutaneous venous accesses, stomas or drains are added.

The patients also stressed how strong feelings of existential loneliness were evoked when their bodies were touched in a nonempathetic way. Common words were not always sufficient for those descriptions and metaphors for animals, e.g., “treated like a pig” were used instead. When the vulnerable body is indifferently touched by someone whom the patient is dependent upon for care, existential feelings of loneliness can arise. One feels loneliness when at someone else’s mercy.

Among patients with a serious cancer diagnosis, bodily changes can occur very rapidly. When that is the case, there is neither time nor opportunity for those who are affected to undergo a psychosocial transition and integrate what is happening emotionally and existentially. This circumstance is another factor that could increase the risk of feelings of unfamiliarity and loneliness.

Experiences of loneliness among next-of-kin who were left alone with responsibilities that they experienced as hard to handle are described in several reports. The fact that the disease is incurable adds a profound existential dimension to the sometimes overwhelming responsibility and the insufficiency the next-of-kin experienced. Mistakes at the hospital, the patient’s inability to eat and insufficient pain control were all transformed into concern about life and death: so were the feelings of powerlessness and loneliness in the next-of-kin.

Methodological considerations

We aimed at a maximum variation sampling, in order to cover as many aspects of the phenomenon as possible. The data should therefore be transferable in palliative care settings in secularized Western societies similar to Sweden. In a qualitative study the results are always context-bound and therefore not possible to generalize, but transfer to other similar contexts.

Implications

Man is basically alone. Existential loneliness is therefore impossible to eliminate and is a basic given for all humans. However, respect and em-
pathy and provision of nursing and care with feeling of mutual togetherness and belonging, may decrease the perception of existential loneliness. This knowledge is most important and it should be useful for all providers of palliative care. Yalom stresses that everyone must carry his or her existential loneliness, no relationship can eliminate it, but “love compensates for the pain of isolation.” We drew a similar conclusion from our study: the power and possibilities in empathic human encounters, also between care providers and patients, may partly compensate for the pain of isolation. Therefore, when patients and next-of-kin are treated with empathic understanding together with the time and attention given, it would be possible for them to relate. This will not eliminate, but at least assuage their feelings of loneliness.

The impact of the physical body and physical suffering as a trigger of existential loneliness was striking in our study. In order to minimize existential loneliness, we have to be observant of all kinds of bodily discomfort, as the body, especially during severe illness, influences the psychological and existential well being. Or as Merleau-Ponty expresses it: we do not only have a body, but in our existences we are bodies. Hands are powerful instruments that we all are provided with and a sensible use of our hands could have the greatest impact.

The body of a person with a life-threatening disease is very vulnerable. When it is touched by “speedy hands, impatient hands” that “hasten to get ready,” those hands do not merely give signals about stress. They limit or make communication and mutual togetherness impossible, and open up for feelings of existential loneliness. On the contrary, sensitive hands can give reassurance and reduce aloneness.

It is not always possible to distinguish between body and soul, especially not in a palliative care setting. The disease induces bodily suffering and these symptoms affect both mind and soul. One of the consequences is heightened awareness of existential loneliness, as shown in this study. Therefore, it is necessary to focus on total care and use all those resources that a multiprofessional team approach can offer.

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REFERENCES


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