Original Manuscript

Nursing Ethics
2019, Vol. 26(5) 1310–1325

10.1177/0969733017748480
journals.sagepub.com/home/nej
SAGE

Existential loneliness: An attempt at an analysis of the concept and the phenomenon

Ingrid Bolmsjö, Per-Anders Tengland and Margareta Rämgård
Malmö University, Sweden

Abstract

Background: According to ethical guidelines, healthcare professionals should be able to provide care that allows for the patients' values, customs and beliefs, and the existential issues that are communicated through them. One widely discussed issue is existential loneliness. However, much of the debate dealing with existential loneliness concludes that both the phenomenon and the concept are quite vague.

Aim: To clarify what constitutes existential loneliness, and to describe its lived experiences. A further aim was to provide a definition of existential loneliness that can function as a tool for identifying the phenomenon and for differentiating it from other kinds of loneliness.

Method: A literature review including theoretical and empirical studies. Different search strategies were used to gather the articles included in the study. The analysis of the empirical studies had an interpretative approach. The articles were also analysed with the aim of providing a definition of existential loneliness. This was done by means of criteria such as language, uniqueness, theory and usefulness. This study is not empirical and does therefore not require an ethics review.

Results: The analysis resulted in two main characteristics. The first one was perceiving oneself as inherently separated (disconnected) from others and from the universe. The second one brings out emotional aspects of EL, such as isolation, alienation, emptiness and a feeling of being abandoned. The empirical findings were divided into two categories: experiences of EL and circumstances in which EL arises. A definition of EL is also suggested, based on the two main characteristics identified.

Conclusion: In order to meet patients' needs, it is an ethical duty for healthcare staff to be able to recognise experiences of EL, that is, to communicate with the patients about these experiences in an appropriate manner. This in turn demands knowledge about existential issues and skills to deal with them.

Keywords

Concept analysis, empirical approaches, existential loneliness, literature review, older people care, person-centred care

Introduction

Old people who are stricken with infirmity and disease and people with severe illnesses are in need of healthcare. When dying and death come closer, existential concerns will often be brought up[1,2] and, as a result, crises might arise. In such cases, the professionals should be prepared to take care of the patients as

Corresponding author: Ingrid Bolmsjö, Department of Care Science, Faculty of Health and Society, Malmö University, Jan Waldenströmsgata 25, 205 06 Malmö, Sweden.
Email: ingrid.bolmsjo@mah.se

well as their close relatives. Today, in the modern healthcare system, an ideal to strive for is to take care of people in a person-centred way. Person-centred care can mean many things, however, but the common goal for the practice is to focus on the patient as a unique person, with individual needs and preferences, rather than on the illness the person is afflicted with. Thus, not merely medical problems should be in focus but also the patients' psychological and existential needs.[3,4] Other important elements that are taken into account in person-centred care are patient participation and involvement, the relationship between the patient and the healthcare professional, and the context where care is delivered.[5,6] Care should, therefore, be based on the patient's experience of his or her situation and his or her individual conditions, resources and restraints.

Because of an unclear understanding of what person-centred care means, different professional groups tend to focus on, or emphasise, different elements within person-centred care.[5] This may lead to a neglect of the existential aspects of care. One reason for this might be that tending to the patient's existential needs is experienced as one of the greatest challenges for healthcare personnel.[7,8] Existential issues that have to be dealt with, especially in palliative care, concern the meaning of life, dependence and decreased autonomy, and guilt and responsibility concerning close relatives.[9] The findings of some studies in care for older people underline that the staff want to discuss existential issues so that they might understand and meet their residents' needs in a better way.[7,10] Most professionals, however, feel that they are not prepared to do so.[11]

Ethical issues are also prominent in care. According to the ICN Code of Ethics, nurses should be able to provide care that allows for the patients' values, customs and beliefs,[12] and it can be assumed that existential issues are expressed and communicated through those cultural dimensions. Thus, it is of great importance that nurses become familiar with the values, beliefs and customs of each specific patient, and hence, it is also important that nurses are familiar with existential concerns. This is, at least partly, a matter of the patient's right to autonomy, involving, for example, his or her decisions about what issues are important to talk about, but it is also a matter of the patient having his or her thoughts and feelings respected in an empathic and 'unconditional' (non-judgmental) way.[13]

In the scientific literature, existential loneliness (EL) has been widely discussed.[14] Both theoretical and empirical studies have been carried out in many different contexts, such as nursing, medicine, psychiatry, psychology, theology and philosophy. Much of the debate concludes that the phenomenon is multifaceted and elusive, and, furthermore, that there is no clear consensus concerning the definition of EL. However, considering the multitude of studies found, we will assume that EL exists, and with this in mind, we think it could be fruitful to take a step towards a clarification of the phenomenon of EL.

Aim

The aim was to clarify what constitutes EL and to describe its lived experiences. A further aim was to provide a definition of EL that could function as a tool for identifying the phenomenon and for differentiating it from other kinds of loneliness.

Our research question was: What kinds of experiences does EL consist of? Answering this question was also expected to contribute to the formulation of a definition of EL – one that might help us differentiate it from other kinds of loneliness. Therefore, we add a preliminary research question: How should a useful definition of EL be formulated? In order to answer these questions, we needed different methodological approaches, one for the literature review and one for the philosophical analysis.

Method concerning the literature review

We started by making a systematic literature review, including a process whereby relevant studies and books were found through a combination of search strategies.[15] The first author carried out the literature search with assistance from an experienced librarian.

The first step of the process was open literature searches in databases, using the key words 'existential loneliness'. In total, we found 111 articles: 64 in Cinahl, 20 of which seemed to be relevant; 14 in PubMed, 13 of which seemed to be relevant and 33 in Psycho Info, 17 of which seemed to be relevant. When comparing the articles from the three different databases, we found that 25 articles were identical to other articles, and thus, out of 50 articles from the three databases, 25 were relevant for our purpose.

After that, we conducted a renewed systematic search (autumn 2015) in the databases PubMed, Cinahl, Psych Info and Web of Knowledge, with the key words 'loneliness', 'feeling alone', 'being alone', 'alone', 'aloneness', 'solitude' and 'isolation', in combination with 'existential'. Further references were found in the literature obtained from the initial search as well as in forward and backward citation searches of studies already known to us. This resulted in 60 articles, which we penetrated. Out of these 60, 16 new articles were found to be relevant.

Finally, in the summer of 2017, we conducted a third database search, in order to see whether any new articles had appeared since the previous search. This time we found four articles that seemed relevant for the study.

In total, 45 articles seemed relevant and were included in the preliminary analysis. They were scrutinised using the following inclusion criteria:

1. Articles that specifically examined EL as a phenomenon among adults;
2. Articles that specifically examined EL as a concept.

Exclusion criteria included the following:

1. Articles using quantitative methodology;
2. Popular literature, newsletters and commentaries;
3. Articles that only mentioned EL;
4. Articles published in languages other than English.

Some of the 45 articles had a quantitative approach and did not meet the inclusion criteria. Quite a few were literature reviews of various kinds, and most of these were also left out, since they only superficially fulfilled the inclusion criteria. Most of the empirical studies were, however, based on interview data and the majority of the studies used phenomenological and hermeneutical analytical approaches. After the final review, 11 empirical articles were included, as they best answered the aim of understanding EL and describing its lived experiences (Table 1).

All the empirical articles included in the study used an interpretative analysis, which was one reason for us to choose such an approach. The two authors I.B. and M.R. were involved in the initial analytical process. We started by reading the texts in their entirety, which led us to formulate a question to be verified in the following analysis: Which aspects and dimensions (constructs) of experiences of EL can be identified in the articles? This question was then used to reveal patterns of meaning structures.[25] Second, each of the studies was analysed in detail and then discussed among all the authors, searching for diverse quotes and paragraphs displaying significant aspects of the phenomenon. Finally, we put together our findings from the reviewed articles and sought a common structure within which our findings could fit. This process resulted in two categories: experiences of EL and circumstances in which EL arises. Within each category, related themes emerged.

When discussing the results found (and categorised), we made use of our preliminary definition of EL, as well as the distinctions made between EL and other forms of loneliness, and other phenomena. Finally, as this study is not empirical and does not involve any participants, no ethical review was required.

Table 1. The qualitative articles used in the study.

Author	Context	Key notions of EL
Nyström et al.[16]	Mental health	Not connecting with others/the world outside Alienation
Erdner et al.[17]	Mental health	Not connecting with others/the world outside Alienation Feelings of isolation Emptiness
Sand and Strang[11]	Palliative care	Not connected with others/the world outside Feelings of sadness
Nyström[18]	Aphasia	Not connecting with others/the world outside
Erdner et al.[19]	Mental health	Not connecting with others/the world outside
Sekse et al.[20]	Cancer	Not connected with others/the world outside Feelings of isolation Abandonment
Ozanne et al.[21]	Chronic illness	Abandonment
Österlind et al.[22]	Care for older people	Not connecting with others/the world outside
Larsson et al.[23]	Care for older people	Alienation Emptiness
Sjöberg et al.[24]	Care for older people	Feelings of isolation Alienation
Avieli et al.[29]	Mental health	Emptiness

Method concerning the concept analysis

In order to find a unique as well as theoretically reasonable and practically useful definition of EL, we read through both the empirical articles and the theoretical articles (including some books and book chapters) found in our review.[i] Furthermore, in order to find defining characteristics of EL, we looked for, and wrote down, paragraphs, sentences, words and quotations which dealt with definitions, demarcations and descriptions of EL. After having sampled these usages, definitions and defining characteristics, we discussed them and organised them.[26]

This process led to a preliminary basic definition of 'existential loneliness', that is, a definition focusing on what was common in the (non-idiosyncratic) uses of the term found in the literature. Finally, in the end of the paper, the empirical findings were used in order to make a further explication of the concept, in the sense that some of the important material found was used to stipulatively improve the definition.[27,28]

In order to find a useful definition, we resorted to the following criteria: Language, which means that the definition should capture how people use the term (e.g. in our sources); uniqueness, which means that it should not overlap fully with other similar terms; theory, which means that it should be formulated in a coherent and precise way (making it easy to pick out instances of EL) and usefulness, which means that the definition should have practical significance. This process requires a compromise since language uses are often varied and contradictory, and we had to decide what language uses provided the most salient characteristics of EL – characteristics that made the definition unique, coherent and precise, and ultimately useful.

This first analytical process resulted in a preliminary categorisation of EL that included two central characteristics: (1) perceiving oneself as inherently separated (disconnected) from others and from the

[i]Some of the theoretical articles were, however, not found useful.

universe[11,16–19,22–24] and (2) emotional experiences, such as feelings of isolation,[11,17,24] alienation,[16,17,23,24] emptiness[17,24,29] and abandonment.[20,21]

EL: a preliminary definition

EL will here be preliminarily defined as the immediate awareness of being fundamentally separated from other people and from the universe, and typically, because of this awareness, experiencing negative feelings, that is, moods and emotions. Some clarification is required, however. That the awareness is 'immediate' illustrates that it is an 'acute' experience, here and now. That emotions of a certain kind 'typically' appear, leaves open the possibility that sometimes they do not, or that the experience might even be a positive one, but that such an experience still should count as EL. Before we turn to the empirical findings, we would like to differentiate between EL and other kinds of loneliness.

Other kinds of loneliness

In order to assess the empirical research concerning EL, we have try to distinguish the condition from other similar concepts, primarily those related to other kinds of loneliness. One criterion that has to be fulfilled, as we saw, is that EL should be seen as a unique phenomenon, in the sense that it can be distinguished from similar phenomena. The reason that this is important is that the different kinds of loneliness will (in most cases) require different care strategies.

Let us start with a distinction between objective and subjective notions of loneliness.[30ii] Our interest lies primarily in subjective kinds of loneliness, such as *feeling* lonely, that is, psychological or emotional loneliness. The objective kinds are less important for our purposes, since they only state (non-evaluative) facts about the world, but we still need them – first, in order to give a more complete picture of the phenomenon of loneliness/aloneness, and, second, because there might be causal connections between these forms of loneliness/aloneness.

The objective kinds of 'loneliness' will here be called spatial ('geographic'[iii]) aloneness and social aloneness. By spatial aloneness, we will mean being separated from other persons in space. Primarily, this means that a person that is physically lonely (alone) lives at a distance from most other people (or is isolated from his or her fellow human beings, for example, in prison or in a monastery). This is a purely descriptive definition, and we attach no value, positive or negative, to it. Neither do we want to claim that spatial aloneness necessarily leads to other kinds of loneliness, even if it seems possible that it could.

By social aloneness, we mean that the person has few relatives, friends, colleagues or other acquaintances that the person regularly socialises with. It can also include the absence of an intimate, 'romantic' relation. Just like spatial aloneness, social aloneness is a descriptive category, in the sense that it does not say anything about whether this is good or bad for the individual. We might, however, guess that it is bad, given what we know about human psychology.[32] Nor does it state whether or not the relations in question are of a high quality. We need other conceptions of loneliness to make this distinction.

Subjective (emotional) loneliness is a notion that we find impossible not to consider to be evaluative, since it is always a kind of suffering (and suffering is bad by definition).[iv] By subjective loneliness, we will mean the emotional experience of having no or few close, intimate or meaningful social relations, including

[ii]Note that the notion of 'loneliness' is not normally used for the objective kinds, so we shall speak of 'aloneness' when specifying these kinds of phenomena.

[iii]A term Yalom uses in passing when discussing existential isolation.[31]

[iv]Ettema et al.[14] use the term 'emotional loneliness'. The only drawback in using this term is that EL might also be considered an emotion.

a partner or a spouse – an experience that is typically accompanied by feelings such as sadness, disappointment and/or hopelessness.

Some remarks on the relation of these definitions are required. Note, first, that you might be spatially alone, but not socially alone, since you might have social relations through channels such as the mail, the telephone/the mobile phone or the Internet. These relations might also be profound, that is, subjectively satisfying. Second, you might be in a state of social aloneness, but not experience subjective (emotional) loneliness. We might, however, assume that social aloneness is a key reason for subjective (emotional) loneliness. Thus, these distinctions are theoretically and practically useful in that they can make these kinds of causal relations visible.

The most important point for this preliminary conceptual discussion is to what extent we can differentiate between subjective loneliness as an emotion related to being socially alone and EL, as another kind of experience or emotion. The crucial difference appears to be this: whereas the first kind of subjective (emotional) loneliness is about lacking intimate social relations, EL (as stipulated so far) is concerned with a more basic lack, namely, a feeling of being fundamentally separated from others and the world, whether or not having a family, friends or other close acquaintances. Thus, you might have close relations and not suffer from subjective loneliness, and still experience EL. With the definition already suggested (as a point of departure), and the other distinctions made, we wanted to examine the empirical findings in the included articles.

Results

The empirical findings concerning EL and related topics will be divided into the two categories experiences of EL and circumstances in which EL arises. Each category contains related themes. In presenting our results, we will accept what the authors of the articles included in this study refer to as EL.

Experiences of EL

In this category, two themes emerged: feelings of alienation and fears.

Feelings of alienation. Within this theme, EL is typically expressed as feelings of alienation, isolation and alien feelings of loneliness in situations when you cannot communicate with others. One old man living in a nursing home said,

> When I am in the dining room I don't hear anyone . . . the only voices I hear are the staff's and what they are talking about . . . They are sitting talking with each other about their own interests . . . and that is nothing that interests me . . . I have never been as lonely as in this place.[24]

One patient, suffering from mental illness, expressed the feeling of alienation like this:

> I have always found it difficult to socialize with others. Maybe I don't want to drag them into my world.[17]

Another patient, also suffering from mental illness, said,

> Maybe I'm not interested in socializing. I feel empty, everything is difficult! Don't fit in, it doesn't matter what I do.[17]

Some of the individuals living with severe mental illness were not able to develop connections with other persons, and one reason for this was difficulties in sharing their own experiences with others. This inability led to problems with having new social experiences, and ultimately to feelings of EL.

According to Nyström et al.,[16] the only 'friends' of the participants in their study were the personnel, and the participants experienced themselves as

> outsiders, alienated from others, even when they [were] together with other people.[16]

The authors interpreted this quote, and other informants' similar narratives, as illustrating EL.

Another group of patients, namely, those suffering from aphasia, experienced EL. For example, when a person felt that she was no longer the same person inside due to the aphasia, this created feelings of isolation, that is, EL increased. One woman who was stricken by aphasia had the following experience:

> The last bus was very crowded. I look at the people. It was like a Brecht play, as if they were wearing masks. I could not see the face behind the masks, and their eyes were like empty hollows. I got off the bus and started to walk home. When I arrived home my husband looked at me. He was also wearing a mask![18]

The following quotation from Nystöm et al. describes how crucial it might be to be able to communicate with other people. If you cannot, an alien feeling of loneliness appears:

> If everything previously well-known appears as strange, and communication with those around you is cut off, then the soul is incarcerated in an impenetrable prison, it must be the loneliest soul in the world.[18]

In the study, older people living in a nursing home experienced it as a prison.[18] According to the authors' interpretation, being excluded from ordinary life and harbouring feelings of loneliness were experiences related to EL.

Fears. This theme includes the following aspects: fear of disappearing from earth, and fear of being forgotten, fear of being abandoned and fear of the process of dying.

Fear of disappearing from earth, and fear of being forgotten. Disappearing from earth and at the same time being forgotten are two interrelated aspects that informants suffering from mental illness described. Two quotations illustrate these fears:

> Disappearing from earth and everything ending.[19]

> Just disappear, not to have a grave or gravestone. No one will visit the gravestone anyway, because I'm not that important.[19]

Another person said,

> 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 . . . [11]

One person expressed the fear of oblivion like this:

> Being extinguished – no one will remember me and I'll be forgotten.[19]

Fear of being abandoned. A further fear was found in a study by Ozanne et al.,[21] where the informants expressed a fear of being abandoned, without having a close relative nearby. One woman verbalised her fear in the following words:

> Then I can also say that due to the disease I am very scared that my husband will die before me. He is my safetynet now.[21]

When death approaches, a sense of losing one's hold on life might produce feelings of being unprotected and 'skinless' and give rise to death anxiety. According to the dialogue below, death anxiety is closely related to a fear of being totally alone:

> 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 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 it is so, or for my own part I know it is so.[11]

In particular, the fact that the informants were going to die alone, and the impossibility to share this event with others, made them experience EL. One patient said,

> Just sit here and suddenly stop existing . . . 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.[11]

In one study, women were interviewed about their experiences after years of survival after having had breast cancer. The findings point to the fact that the informants had gone through an overwhelming experience, including feelings of EL. Loneliness and uncertainty lasting for years after surgery gave rise to feelings of being abandoned, this time by the healthcare system. One woman said,

> I felt like, well. 'Now you're done . . . through . . . out you go!'[20]

Fear of the process of dying. Patients who were in a situation where no cure was possible, and who were becoming more and more dependent on other people due to the subsequent loss of faculties, expressed feelings of EL. For example, living with a life-threatening disease, such as ALS, gave rise to feelings of anxiety about the process of dying, which put its stamp on the whole of life. The quotations below illustrate those patients' feelings:

> But it is the question around it all, that you can't get an answer for, if there are any drugs, that you don't know how long it will take . . . That's the scary thing.[21]
>
> . . . it's not death itself I am afraid of, but rather the way I will die.[21]

Common to all of these fears is that they appear to be central aspects of experiences of EL.

Circumstances in which EL arises

Under this heading, we will present different circumstances which can be seen as contributing causes for experiences of EL.

To be dying. Impending death and thoughts of death seem to be the strongest sources for experiences of EL. When death is coming close, thoughts of what it means to be dead are related to being totally alone:

> 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.[11]

To have an unhealthy body. Another situation which creates EL is when the body changes and becomes unhealthy or dysfunctional. Different kinds of changes due to bodily impairments will lead to feelings of EL. Thus, the body seems to play an important role in these experiences:

> 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).[11]

Another description of a patient's situation also illustrates the anxiety caused by an increasingly dysfunctional body:

> He says like, 'if I could just use my hand', he says, 'that's the worst of it all, this hand' . . . and the incontinence and that he can't . . . it's the worst thing he knows. To have to rely on other people and to use diapers and all that, ugh, he thinks it's horrible . . . he can't do anything . . . he says, 'I'm totally worthless' . . . he also says that he's pitiful . . . he wants to manage by himself . . . but he can't.[23]

The examples illustrate that an unhealthy body and obvious signs of illness might trigger and create experiences of EL.

Fear of the recurrence of illness. In a situation where the person has recovered, but where the illness might reoccur, experiences of EL will also often appear. The quotation below illustrates the fact that fear of what is going to happen in the future concerning the risk of recurrence is related to fear of dying:

> It has something to do with the graveness of it all . . . and it's clear that cancer affects your whole life situation and future, and you wonder what's going to happen . . . You kind of never get over it![20]

Not being able to communicate. Not being able to communicate is a situation where you can experience feelings of EL. One patient, struck by aphasia, expresses this experience by means of a metaphor:

> The soul is incarcerated in an impenetrable prison.[18]

When you cannot express yourself verbally, you can try to communicate with your body. According to the interpretation of a significant other of an older person living in a nursing home, the older person experienced EL in the situation described in the following quotation:

> . . . then she's sitting like this, in this way [hanging over the table], I usually say that it's like a computer that stalls . . . that's shutting down, and that's how my mom sits.[23]

Not being listened to or understood. A final theme emerged in a few of the sources, namely, the fact that EL might appear in situations where the individual does not feel that others are attentive to his or her needs to express himself or herself, especially in relation to impending death:

> 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.[22]

Similar experiences are found by Erdner, that is, that the informants felt alone even when they were with other people:

I feel like an odd person when I am with other people.[17]

Another person expressed the lack of genuine communication in the following way:

I find it difficult to chit-chat.[17]

In one study, the authors found that being met with indifference gave rise to EL. One old man sitting in a wheelchair said,

It annoyed me . . . if there is something that is not done properly, I tell them . . .

Don't they listen to you then?

No, not at all. They take it for granted that you are already 'lost' when you come here . . .[24]

Discussion

In this discussion, we will bring up several themes: kinds of loneliness, facing death, EL as a result of lack of genuine communication, homelessness and loneliness, and person-centred care and EL. Finally, the question about the definition of EL will be returned to.

Kinds of loneliness

One of the criteria we set up was that EL should be seen as a unique phenomenon, clearly demarcated from other types of loneliness (and other phenomena). The empirical studies reviewed, however, also deal with other aspects than EL, such as other kinds of subjective (emotional) loneliness. There are several instances where it is probable that the phenomena discussed are not (only) existential, but concern other kinds of loneliness. The claim that 'I have nobody' appears to be one such case. Another informant discusses what it means to die, but seems to switch to social and emotional loneliness when adding 'And being alone here at home. I don't want to sit here and deteriorate and struggle and experience a hard time all alone'.[11] Another woman is, as we saw, afraid that her husband will die before her. She needs him, so that she 'can be at home'. This appears to be a different kind of fear, obviously also a serious one. But it has to be addressed in another way, for example, through the creation of possibilities to have real social relations.

We find that according to nurses and other healthcare personnel interviewed,[22,23] experiences of these different kinds should be discussed with the patient in order to alleviate feelings of isolation, anxiety and all kinds of loneliness. It appears, however, that the healthcare is better at understanding social and emotional loneliness than EL.[33] If this is true, and whether we want to address EL or other kinds of loneliness, the nurse has to be able to communicate with the patient in a profound way, and be able to provide the care appropriate for each situation.

Facing death

The loneliness described by the informants is existential and ever present, colouring the experience and meaning of their whole lives. The loneliness these people expressed was so profound that it reached 'an ontological level', meaning that it touched upon the fundamental question of what it is to be a human being – a being conscious of her own death.[32] One respondent described his feelings thus: 'My God, why have you left me . . . it's a sore in the soul to be left, there's a depth to loneliness . . . a pain'.[34]

On a 'mundane' level, we all know that we are going to die. But on a deeper level, this insight becomes more obvious when we face a crisis, such as being afflicted with a severe illness. At such moments, the person affected, or a relative of that person, needs professionals, such as a nurse, to be prepared to meet these profound experiences and see them for what they are.

EL as a result of lack of genuine communication

The experience of facing death does not have to be interpreted as concerning literal death. Granerud and Severinsson[35] found loneliness to be a main theme for individuals with serious mental illness struggling to integrate socially into the community. Many of these individuals are socially and emotionally lonely,[36] but they feel alone even when they are together with other people.[37] This indicates that their experiences are also of an existential character. A study participant responded, 'I am alone wherever I am',[35] that is, also among other people. One reason for this loneliness, even with other people around, is the tendency of some people, who are sometimes afraid of talking about death and illness, to engage in small talk. We saw one interviewee complain about this: 'I find it difficult to chit-chat'.[17]

Thus, not being listened to when communicating what is essential to the person, not least thoughts and emotions related to illness and death, could be likened to 'spiritual' (psychological, emotional) death, in the sense that the person risks losing contact with her deepest self,[13] that is, risks becoming incongruent. This is an example of what Yalom calls 'intrapersonal isolation'.[31] Incongruence, arising out of this kind of denial of what is important to the individual, creates suffering and also makes life more difficult, since the individual might lose touch with parts of her experiential self - parts that are needed in order to govern life well.[13]

This is in line with Öhlén's observation that EL is an experience that appears where the person is not listened to, or understood, by others, that is, when she is 'not met in her life-world' (Öhlén cited in Brülde[38]). We might, then, conclude that EL also arises in the absence of deep meaningful relations, specifically, but not only, when facing (literal) death. Not having anyone to communicate with is in a sense equivalent to dying 'spiritually' (psychologically, emotionally).

Homelessness and loneliness

Furthermore, some of those with a mental illness yearned for a place where they could feel accepted, a real home.[29] Those who lived alone were grateful to have their own apartment, but never really 'felt at home', something that the phenomenologist Fredrik Svenaeus sees as a fundamental aspect of being ill.[39] He uses Martin Heidegger's notion of 'homelessness' to characterise illness in general.[39,40] Thus, it appears that two fundamental existential experiences, 'homelessness' and EL, might go together. In some cases, they might refer to the same kind of experiences. One way to interpret the idea of homelessness (but also EL) is that life, when you are seriously ill, or when facing death, loses its meaning for the person. This goes especially for people with mental illnesses, where life does not make sense any more. Erdner et al.,[17] for example, emphasise that patients have to 'be helped to experience that life has a *meaning* despite their disability'. Consequently, it can be inferred that if those that care for people with mental illnesses become better at paying attention to the dimensions of EL, and the meaning- and homelessness experienced, they also become better at helping to alleviate the suffering experienced.[39]

Person-centred care and EL

One crucial idea in person-centred care is that all aspects of the individual should be attended to, and all kinds of complaints listened to. Healthcare (at least in the more developed countries) is in general very good

at treating patients' physical problems, as well as many of the mental ones. It is obvious from the studies we have presented that the existential experiences of loneliness are not equally well taken care of in the treatment process. One question that arises is, whose responsibility is this? The answer primarily has to do with education, that is, the question of who has acquired the required tools to meet existential needs. Given that those needs in general require specific skills, the right person to meet the individual could, for example, be a psychologist, a psychotherapist, a counsellor or a priest. However, the professional group closest to and most in touch with the patients are nurses (leaving aside here nurses' assistants). Therefore, nurses appear to be the ones most suitable to handle the problem. However, it seems clear that in most places today many nurses are not prepared educationally to master these kinds of situations, nor do they always have the time. There is no 'quick fix' for existential problems. The time issue apart, what we need are better educated nurses, especially outside of palliative care, and part of this education has to do with recognising the patients' existential needs, and, in cases of not having the required tools to deal with such needs, knowing whom to turn to for assistance.

Furthermore, ethically, we should require that healthcare personnel care about what is most important for the suffering individual. This is stated in the ICN code of ethics.[12] Person-centred care therefore necessitates knowledge about how to conduct conversations about existential issues in an ethical way, as well as time and opportunities for such conversations. Moreover, if knowledge, time and/or opportunities are lacking, the personnel risk being exposed to 'moral stress', which might lead to 'psychological disequilibrium', characterised by feelings of '[f]rustration, anger and anxiety', and, in the end, to worse patient outcomes.[41]

These questions are not, however, 'built into' the healthcare organisation, and further education (i.e. professional development) usually focuses on technical and medical aspects of care, rather than on existential or moral issues. Specialists in palliative care, nurses and others, are obviously much better equipped to take care of this kind of suffering, but not all palliative care is provided in palliative care units.

To sum up, EL appears in many different life situations, not always, as we have seen, connected to end-of-life care, and it involves various kinds of fears. Facilitating the creation of meaning for patients in states of chronic suffering, as well as for patients with severe mental ill health, or for patients facing death, is part of person-centred care and emphasised in ethical guidelines for nursing. Nurses, both inside and outside palliative care, therefore need to pay more attention to these experiences, and managers have to realise the need for this kind of care.

The definition

We started with a preliminary definition of EL, defining it as an awareness of being fundamentally separated from other people and from the universe, and typically, because of this awareness, experiencing negative feelings (i.e. moods and emotions). We shall here develop this definition based on some of the empirical data presented in the study.

One feature that appears over and over again in the interviews is the awareness of death. It seems obvious that this awareness lies at the heart of EL, implicitly or explicitly. Thus, death (or the fundamental awareness of being mortal) is one aspect that could be added to the definition. This, of course, accords with general insights in existentialism and existential psychotherapy.[31,40,42] Another insight is the fact that people, especially in life-threatening circumstances, or in other kinds of crises, such as mental illness, or aphasia, need someone to communicate with 'on a deeper level', or else feelings of EL will occur. We saw that one patient with mental health problems complained about people chit-chatting, implying that the person needed, and would have preferred, an encounter on a more fundamental, psychological level, that is, to be in an 'authentic' I-Thou relation.[43]

We have already suggested that to lack a genuine and empathic listener is to 'die' a little, mentally or 'spiritually'. As Carl Rogers would have it, and assuming that mental health requires a deep communicative relation to another person, or several, the suffering person who lacks such a listener risks becoming less genuine (congruent), that is, risks losing contact with her deeper self.[13] This, of course, goes for all people with a similar lack, regardless of their various kinds of problems or specific communicative needs, but especially for people who are seriously ill, who are dying or who have thoughts about their own (or a family member's) impending death.

A definition that takes these ideas into consideration is the following:

EL can be understood as the immediate awareness of being fundamentally separated from other people and from the universe, primarily through experiencing oneself as mortal, or, and especially when in a crisis, experiencing not being met (communicated with) at a deep human (i.e. authentic) level, and typically therefore experiencing negative feelings, that is, emotions or moods, such as sadness, hopelessness, grief, meaninglessness or anguish. This, then, is our tentative suggestion for a definition that might be used for identifying EL, for differentiating it from other kinds of loneliness, and for thinking about ways in which the experience can be met and, perhaps, alleviated.

Strengths and limitations

When the research problem is complex, as in this study, more than one methodological approach is often needed. The main strength of this study is that we have carried out both a philosophical analysis of the concept of EL and an analysis based on empirical studies of the phenomenon, something which should make for a more profound understanding of EL. A limitation is that in some articles, it is the authors' interpretations of the meaning of EL we have to present in the result section and this second-hand information might affect the trustworthiness of the result. However, most of the articles included in our result are interview studies containing quotations, that is, first-hand information, from patients.

Conclusion and further reflections

Thus, the educational system, and in particular nursing education, needs to pay more attention to EL, and it also needs to take into consideration, in its policies, methods for conducting existential dialogues, whereas the healthcare system needs to create space for addressing these issues when the skills are in place. Nursing is a kind of *praxis*, that is, a unity of theory and action that has to do with intellectual, practical, intuitive, sensory and other kinds of knowledge. According to Freire,[44] authentic dialogues are the basis of praxis, and without dialogue praxis is not possible. To create existential meaning for patients and reduce their loneliness, the educational system has to help nurses turn this idea of dialogue into a skill, something which, as already noted, requires an educational system that implements this aspect of communication in nursing.

In realising these educational needs, we should also note that professions have different views on what palliative care amounts to, and that there is a need for a more coherent view within, for example, the palliative teams, where, in general, more room for discussion among the team members has to be created.

Moreover, we should be aware that care is not equitable today, and that groups of patients are treated differently, depending on kind of illness, place and country, and that addressing EL, like any kind of suffering, is also a question of equity and social justice.

Apart from the fact that patients' experiences should be respected and listened to (for ethical reasons), one final, and important, reason for professionals to be aware of and deal with EL, that is, meet the patients with acceptance and allow them to be authentic in that kind of experience, is that it might lead to a positive process of growth, creativity, meaning creation and human development. This is not a prominent

feature in the articles studied (and therefore not part of the result), but it is emphasised by Ettema et al.[14] as an important feature of EL, and is found in quite a few earlier texts.[45–47] experiencing EL offers a possibility to find more meaning in life, perhaps even when dying – a possibility that should be recognised and valued.

We should also remember that many existential philosophers find that the awareness of death intensifies life, which, thus, makes this awareness something to cherish, not fear. As Olson[48] puts it: 'The courageous man [sic!], on the contrary, will embrace the consciousness of death as an agent of liberation'. That attitude is, of course, easier to adopt for the healthy person, than for the ill or dying one.

Avenues for further research

With regard to further research, it would be fruitful to study EL more closely by interviewing patients with a specific illness trajectory and/or younger patients, in order to present a wider variety of experiences of EL. Another possibility is to extend the source material by analysing texts by novelists and spiritual writers and compare their descriptions of EL to those of patients, significant others and healthcare personnel.

Acknowledgement

We would like to thank Katarina Graah-Hagelbäck for language revision of the manuscript.

Conflict of interest

The author(s) declared no potential conflicts of interest with respect to the research, authorship and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This study has been funded by grants from the Vardal Foundation [2014-0127].

References

1. Greisinger AJ, Lorimor RJ, Aday LA, et al. Terminally ill cancer patients. Their most important concerns. *Cancer Pract* 1997; 5: 147–154.
2. Ågren Bolmsjö I. *Existential issues in palliative care*. PhD Thesis. Faculty of Medicine, Lund University, Lund, 2002.
3. WHO Expert Committee on Cancer Pain Relief and Active Support Care. *Cancer pain relief and palliative care: report of a WHO expert committee [meeting held in Geneva from 3 to 10 July 1989]*. Geneva: World Health Organization, 1990.
4. Udo C. The concept and relevance of existential issues in nursing. *Eur J Oncol Nurs* 2014; 18: 347–354.
5. Kitson A, Marshal A, Bassett K, et al. What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy. *J Adv Nurs* 2013; 69: 4–15.
6. Rämgård M, Blomqvist K and Peterson P. Developing health and social care planning in collaboration. *J Interprof Care* 2015; 29: 354–358.
7. Andersson M, Hallberg I and Edberg AK. Old people receiving municipal care, their experiences of what constitutes a good life in the last phase of life. *Int J Nurs Stud* 2008; 45: 818–828.
8. Beck I, Törnquist A, Broström L, et al. Having to focus on doing rather than being-nurse assistants' experience of palliative care in municipal residential care settings. *Int J Nurs Stud* 2012; 49: 455–464.
9. Bolmsjö I. Existential issues in palliative care: interviews of patients with amyotrophic lateral sclerosis. *J Palliat Med* 2001; 4: 499–505.

10. Bolmsjö I, Edberg A-K and Lilja Andersson P. The use of drama to support reflection and understanding of the residents' situation in dementia care: a pilot study. *Int J Older People Nurs* 2014; 9: 183–191.
11. Sand L and Strang P. Existential loneliness in a palliative home care setting. *J Palliat Care* 2006; 9: 1376–1387.
12. International Council of Nurses. *The ICN code of ethics for nurses*. Geneva: International Council of Nurses. 2012.
13. Rogers CR. *On becoming a person: a therapist's view on psychotherapy*. New York: Houghton Mifflin Company, 1991, pp. 283–4, p. 125 ff.
14. Ettema EJ, Derksen LD and van Leeuwen E. Existential loneliness and end-of-life care: a systematic review. *Theor Med Bioeth* 2010; 31: 141–169.
15. Conn VS, Isaramalai S, Rath S, et al. Beyond MEDLINE for literature searches. *J Nurs Scholarsh* 2003; 35: 177–182.
16. Nyström M, Dahlberg K and Segesten K. The enigma of severe mental illness: a Swedish perspective. *Issues Ment Health Nurs* 2002; 23: 121–134.
17. Erdner A, Magnusson A, Nyström M, et al. Social and existential alienation experienced by people with long-term mental illness. *Scand J Caring Sci* 2005; 19: 373–380.
18. Nyström M. Aphasia – an existential loneliness: a study of the loss of the worlds of symbols. *Int J Qual Stud Heal* 2006; 1: 38–49.
19. Erdner A, Andersson L, Magnusson A, et al. Varying views of life among people with long-term mental illness. *J Psychiatr Ment Health Nurs* 2009; 16: 54–60.
20. Sekse R, Raaheim M, Blaaka G, et al. Life beyond cancer: women's experiences 5 years after treatment for gynaecological cancer. *Scand J Caring Sci* 2010; 24: 799–807.
21. Ozanne A, Graneheim U and Strang S. Finding meaning despite anxiety over life and death. *J Clin Nurs* 2013; 22: 2141–2149.
22. Österlind J, Ternestedt BM, Hansebo G, et al. Feeling lonely in an unfamiliar place: older people's experiences of life close to death in a nursing home. *Int J Older People Nurs* 2017; 12: 1–8.
23. Larsson H, Rämgård M and Bolmsjö I. Older persons' existential loneliness, as interpreted by their significant others – an interview study. *BMC Geriatrics* 2017; 17: 138.
24. Sjöberg M, Beck I, Rasmussen HB, et al. Being disconnected from life: meanings of existential loneliness as narrated by frail older people. *Aging Ment Health* 2017; 17: 1–8.
25. Jensen LA and Allen MN. A synthesis of qualitative research on wellness-illness. *Qual Health Res* 1994; 4: 349–369.
26. Gerring J. *Social science methodology: a criterial framework*. Cambridge: Cambridge University Press, 2001, pp. 65–86.
27. Carnap R. *The logical foundation of probability*. Chicago, IL: The University of Chicago Press, 1971, pp. 3–8.
28. Nordenfelt L. *On the nature of health: an action-theoretic approach. 2nd revised ed*. Dordrecht, The Netherlands: Kluwer Academic Publishers, 1995, p. 11.
29. Avieli H, Mushkin P, Araten-Bergman T, et al. Aging with schizophrenia: a lifelong experience of multidimensional losses and suffering. *Arch Psychiatr Nurs* 2016; 30: 230–236.
30. Brülde B and Fors F. Den svenska ensamheten: om hur olika former av ensamhet påverkar vårt välbefinnande [The Swedish loneliness: how different forms of loneliness affect our well-being]. In: Bergström A, Johansson B, Oscarsson H, et al. (eds) *Fragment*. Gothenburg: SOM Institute, University of Gothenburg, 2015, pp. 47–61.
31. Yalom ID. *Existential psychotherapy*. New York: Basic Books, 1980, p. 29 ff, p. 353, 354.
32. Brownlee K. A human right against social deprivation. *Philos Quart* 2013; 63: 199–222.
33. Sand L. *Existential challenges and coping in palliative cancer care: experiences of patients and family members*. PhD Thesis, Karolinska Institutet, Solna, 2008.
34. Nilsson B, Nåden D and Lindstrom UA. The tune of want in the loneliness melody: loneliness experienced by people with serious mental suffering. *Scand J Caring Sci* 2008; 22: 161–169.

35. Granerud A and Severinsson E. The struggle for social integration in the community – the experiences of people with mental health problems. *J Psychiatr Ment Health Nurs* 2006; 13: 288–293.
36. Davidson L. *Living outside mental illness: qualitative studies of recovery in schizophrenia*. New York: New York University Press, 2003, p. 152 ff.
37. Erdner A, Nyström M, Severinsson E, et al. Psychosocial disadvantages in the lives of persons with long-term mental illness living in a Swedish community. *J Psychiatr Ment Health Nurs* 2002; 9: 457–463.
38. Brülde B. *Lycka och Lidande. Begrepp, metod och förklaring* [Happiness and suffering. Concepts, method and explanation]. Lund: Studentlitteratur, 2007.
39. Svenaeus F. Sjukdomens mening: det medicinska mötets fenomenologi och hermeneutik [The meaning of illness: the phenomenology and hermeneutics of the medical encounter]. Stockholm: Natur och Kultur, 2003, p. 66 ff.
40. Heidegger M. *Varat och tiden, del 2* [Being and Time, part 2]. Göteborg: Daidalos, 1993, p. 15ff.
41. Lützén K, Blom T, Ewalds-Kvist B, et al. Moral stress, moral climate and moral sensitivity among psychiatric professionals. *Nurs Ethics* 2010; 17: 213–224.
42. Sartre J. *Being and nothingness: an essay in phenomenological ontology*. New York: Philosophical Library, 1971, p. 531 ff.
43. Buber M. *I and Thou*. New York: Charles Scribner's Sons, 1970.
44. Freire P. *Pedagogik för förtryckta* [Pedagogy of the oppressed]. Stockholm: Gummesson, 1972, p. 89 ff.
45. Moustakas CE. *Loneliness*. Englewood Cliffs, NJ: Prentice-Hall, 1961, p. 33 ff.
46. Lindenauer GG. Loneliness. *Int J Emot Educ* 1970; 10: 87–100.
47. Francis GM. Loneliness: measuring the abstract. *Int J Nurs Stud* 1976; 13: 153–160.
48. Olson RG. *An introduction to existentialism*. New York: Dover Publications, 1962, p. 196.