

# Experiences of living with a deteriorating body in late palliative phases of cancer

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## Purpose of review

The trajectory of living with incurable cancer is characterized by increasing deterioration of the person's body. The aim of this review is to gain insight into the expert knowledge people have about their own lived experiences of bodily deterioration and symptoms in late palliative phases of cancer, and suggest a framework for understanding and studying these experiences.

## Recent findings

When assessing the presence, severity and distress of symptoms and problems experienced by patients, it is important to carefully consider choice of instruments, which by nature, tend to target distinct problems, and expand assessment to include narrative approaches. Deterioration of the body and symptom distress can have dire consequences for the individuals, as these threaten the intactness of the person, may lead to desire to end one's life, can act as determinant of place of death, and dominate the sick person's existence.

## Summary

Understanding the meaning bodily deterioration and symptoms have for patients is intrinsic for optimization of supportive interventions. We suggest that improved integration of knowledge from logical scientific and narrative approaches in research aiming to generate empirical and/or theoretical knowledge, and cross-fertilization of research from closely related areas can contribute to improving care for this vulnerable group of patients.

## Keywords

bodily deterioration, cancer, life world, palliative care, physical symptoms

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## Introduction

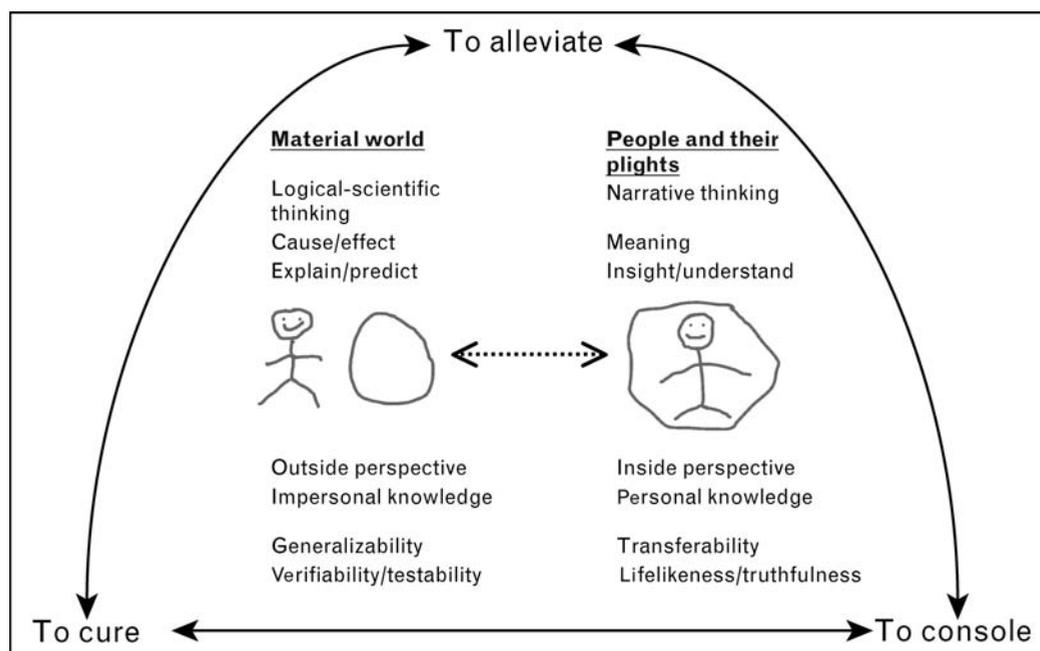
The trajectory of living with incurable cancer is characterized by increasing deterioration of the person's body. It is well recognized that quality of life when living with advanced cancer in late palliative phases of cancer is often impaired, due to a wide variety of symptoms, bodily problems and concerns [1]. Patients in this phase of cancer have been found to have a median of 11 symptoms [2], which may often remain undertreated. For example, Laugsand *et al.* [3] recently found that one-third to half of patients with a symptom observed as moderate or severe received no treatment aimed at reducing its intensity [3]. Chochinov *et al.*'s [4] investigation into end-of-life distress among 253 patients receiving palliative care clarified the strong relationship between bodily deterioration and the experience of dignity. We interpret these results as indicating how a weak and sick body impacts on all aspects of a person and her/his life situation, for example experiencing physical distress, not being able to continue usual routines and carrying out important roles, not feel-

ing like the person one once was, and not being able to perform tasks of daily life [4].

Epidemiological and survey research has extended our knowledge of the extent of symptoms and problems experienced by people with cancer in late palliative phases, factors related to the experience of such bodily problems, and how such problems are treated within the healthcare system [1,3,5,6]. However, knowledge about the life world experienced by people living with bodily changes as death approaches remains more limited.

In this article, we aim to complement existing knowledge by exploring recent research literature focusing on the experiences of people with cancer in late palliative phases of bodily deterioration with its resulting problems, from their own perspectives. Whereas the vast majority of studies published recently about symptoms and bodily deterioration of patients with cancer in late palliative phases are based on a 'logical scientific approach' [7], such approaches are not most appropriate for gaining

**Figure 1** A graphic representation, inspired by Bruner [7], of the interplay between the two ways of thinking necessary for researching and supporting patients in palliative care living with a deteriorating body



in-depth knowledge about individuals' experiences. In this review, we focus on literature derived from a second manner of organizing knowledge, that is, a 'narrative approach' [7]. One graphic representation of the interplay between these modes of knowledge in late-stage palliative care contexts is illustrated in Fig. 1.

These two approaches reflect the different traditions of healthcare originating from ancient Greece, the Hippocratic and the Asklepiian traditions. The Hippocratic tradition, reflecting a logical scientific approach, is committed to investigating the rational, scientific basis of medicine, with the central doctrine that every disease and human ailment has a course which can be discovered and treated, and that this knowledge is generalizable. The Asklepiian tradition, reflecting a narrative approach, focuses on the unique individual, with his/her own story and values. In this tradition, healing and well being are viewed as stemming from within the individual [8].

In this article, we rely primarily on research derived from the Asklepiian, or narrative tradition, while recognizing the importance of combining different types of knowledge in all efforts to improve care. We have examined approximately 2000 titles published between October 2008 and March 2010, and have more thoroughly read approximately 450 abstracts and 50 articles, finding only seven articles which met our criteria. By perusing this literature, we hope to gain insight into the expert knowledge people have about their own lived experiences of

bodily deterioration, problems and symptoms in late palliative phases of cancer, and suggest a framework for understanding and studying these experiences. By doing so, this knowledge becomes more accessible for joint efforts to alleviate such problems at the end of life.

### Experiences of living with a deteriorating body

We begin by first presenting research combining logical scientific and narrative approaches, followed by studies using narrative approaches alone. We thereafter make some suggestions towards a framework for furthering investigating experiences of living with a deteriorating body.

#### Research combining logical scientific and narrative approaches

We found one article that combined narrative and logical scientific approaches to investigate experiences of bodily deterioration at the end of life with cancer [9<sup>\*</sup>]. Tishelman *et al.* [9<sup>\*</sup>] first used a free-listing approach derived from anthropology at several time-points, asking 343 patients with inoperable lung cancer to reply to an open question about what they found most distressing at present. These responses were then compared to three standardized quality-of-life and symptom questionnaires, to see if the problems described were adequately assessed. Not unexpectedly, 90% of patients said that bodily problems were most distressing at some time-

point, with such problems often concerning fatigue and weakness, pain, gastro-intestinal symptoms, dyspnea and cough. A notably wide range of other symptoms and bodily problems were described as most distressing by 40% of the sample, although most were not assessed by the standardized questionnaires examined. Over one-quarter of patients were unable to describe their distress in terms of specific symptoms, but instead responded with overarching or composite statements. Twenty-seven percent of these very symptomatic patients close to the end of their life reported some aspect of their contact with the healthcare system to be the cause of most distress. Few of the composite statements were assessed by the instruments, and only one questionnaire marginally assessed issues related to iatrogenic distress. This study thus highlights the need to both carefully consider choice of instruments, which by nature, tend to target distinct problems, and to expand means of assessment to include narrative approaches. Lindqvist *et al.* [10] also points to the importance of complementing structured questionnaires with narrative approaches in their work based on men with hormone refractory prostate cancer in late palliative stages. Shah *et al.* [11], based on their inductive study of what 'bothers' 286 palliative care patients most, also point to the importance of using this simple, open question in initial clinical consultations [11].

### Research using narratives approaches

The articles which we accessed from the review period used narrative approaches to illuminate relationships between bodily distress and the intactness of the person, temporality, the desire to end one's life and determining place of care

#### *Bodily distress as a threat towards the intactness of the person*

According to Cassell [12], suffering occurs when a state of distress threatens the 'intactness' of a person. Narrative research supports this understanding by showing how bodily deterioration and symptoms undermine identity [13] and dignity [14,15]. Narrative research highlights what has been described as a split between a dying person's bodily experiences and his/her understanding of these experiences, as the body becomes separated from the self [16], or as Rasmussen *et al.* [17] describe, a sense of not feeling 'at home' in one's body arises. Lawton [13] has termed this, moving from being a 'body subject' to a 'body object' in her seminal ethnographic study of a palliative care unit.

A recent phenomenological study adds more data in support of these theories. McCarthy and Dowling [18<sup>•</sup>] illuminate how six patients with non-small-cell lung cancer became wary of their bodies, as new bodily problems were interpreted as indicating a return of their cancer. Fatigue was experienced as particularly debilitating in its adverse affects on daily life. This study thus provides a

further description of how individuals in late palliative phases of cancer lose their 'taken-for-granted' body [19,20] or, to use Rasmussen *et al.*'s [17] term, the body they felt 'at home' with.

One of the most feared and distressing symptoms associated with cancer is pain [21]. Insights gained from research using a narrative approach show that understanding the personal and culturally determined meaning symptoms have for patients are intrinsic to the optimal development of supportive interventions [21,22,23]. No study in the review period has been located which addresses this important area of research.

#### *Temporal aspects of bodily distress*

Lindqvist *et al.*'s [24<sup>•</sup>] in-depth narrative analysis of repeated interviews with two men with hormone refractory prostate cancer in late palliative phases pointed to interesting features in the experience of time as death approached. They found that temporal awareness changed as the disease progressed and death approached, such that bodily problems in the present dominated the interviews, with reflections related to the past and the future diminishing. Pain, fatigue, nausea, and other bodily problems figured largely in this change, leaving little space for much apart from attending to bodily needs in a present dominated by the experience of a deteriorating body.

#### *Bodily distress in relation to the desire to end one's life*

Previous research aiming to understand factors that support or undermine a person's will to live has shown that will to live is influenced by bodily distress (e.g. uncontrolled pain, shortness of breath) [25,26], as well as psychological (e.g. desire for death and depression) [27,28] and existential issues (e.g. being a burden to others, loss of dignity, meaning, and purpose) [15,29,30].

A few recent articles focus on the impact of bodily symptoms and distress as leading to a desire to end life through active suicide; ceasing to eat and drink; and requests for euthanasia. Two case descriptions and one study inspired by grounded theory give insight into meaning of dire consequences of living with bodily distress. Berry [31<sup>•</sup>] describes the case of a 52-year-old woman with intractable pain who elected to forego eating and drinking to end her suffering, and discusses how hospice staff respected the patient's choice at the same time as they intervened as much as possible to relieve her pain and discomfort [31<sup>•</sup>]. Sneesby [32<sup>•</sup>] describes the challenging case of Bernie, an 84-year-old man with end-stage cancer and dominant symptoms of abdominal pain, total constipation and fecal vomiting. Bernie intended to commit suicide if his symptoms did not improve. After a week of palliative care treatment, his condition deteriorated and he attempted suicide, and died despite

resuscitation as a result of multisystem failure. This difficult ethical dilemma is discussed in relation to the need for staff to consider legal, moral and ethical aspects to improve clinical practice [32<sup>•</sup>].

Pasman *et al.* [33<sup>••</sup>] explored the concept of unbearable suffering in the context of unfulfilled requests for euthanasia, finding different perspectives among patients and physicians on what constitutes unbearable suffering. Patients placed greater emphasis on psychosocial suffering, for example dependency and deterioration, in comparison to physicians who seemed to have a narrower perspective, primarily referring to bodily suffering. Both perspectives are important to consider, with the interaction between them of particular interest when seen in light of Chochinov *et al.*'s [4,14] previous work on components of dignity at the end of life and Kellehear's [34] recent work on dying and human suffering. Kellehear [34] pointed to the importance of a theoretical exchange between theories on suffering and on end-of-life experiences, to further develop both areas of research.

#### *Bodily distress as determinant of place of death*

One quality indicator often referred to in end-of-life care is whether the patient was able to end his/her life in their place of choice [35]. Bodily distress plays a major role even in this regard. In Fisher and Colyer's [36<sup>•</sup>] phenomenological study of six severely ill patients, they show how the decision to be admitted to an inpatient hospice was driven by pain, rather than choice. The experience of overwhelming pain was so great that admission to the hospice was a matter of necessity rather than choice, and thereby had consequences for all subsequent decisions for these patients.

#### **Frameworks for furthering investigation**

Paterson's [37] seminal work on the experience of chronic illness has shown that in order to make sense of their world, chronically ill people experience a continually shifting process between having a perspective of wellness and a perspective of illness in the foreground. Lindqvist *et al.* [38], in their studies of men with hormone refractory prostate cancer in late palliative phases, found a strikingly similar process even at the end of life. Lindqvist *et al.* argue that one intrinsic meaning of bodily problems is in how they influence the cyclical process of an individual's losing and reclaiming wellness. Understanding, and, to some extent, being in control of, bodily problems makes it possible for a person, even in late palliative phases, to experience wellness. When bodily problems increase or change or become a hinder in daily life, or when new bodily problems develop, the experience of being ill becomes more central, with a sense of wellness receding into the background [38].

We are well aware that time along a sickness trajectory impacts strongly on people's bodily experiences and how the meaning of these experience is continually constructed and reconstructed. We suggest here that in addition to this, meanings of bodily changes are also continually evaluated and re-evaluated by each individual in regard to the cyclical shifting between a sense of wellness and illness noted by Lindqvist and colleagues [38,39] and illustrated here by a quote from a man participating in their study:

But of course, as soon as a sickness ... makes itself known dramatically through pain, of course you don't feel healthy...you feel sick, you would be a strange creature if it wasn't like that I think...but that minute or moment or hour or day or week that it disappears from your radar...well then you don't feel like you're sick.

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#### **Conclusion**

We recognize the importance of integrating knowledge from both logical scientific and narrative approaches in research aiming to generate empirical and/or theoretical knowledge which can be used to improve patient care. Our experiences in conducting this review highlight a number of problems in achieving this integration. One difficulty is in accessing relevant research about bodily experiences (see also [6]), as we share no comprehensive professional language, instead using a wide variety of terms to convey knowledge and understanding about the body, suffering and dying. The difficulties this creates in finding literature using a logical scientific approach are further exacerbated in research using a narrative approach, as has been previously noted [40–42]. Narrative research suffers from a lack of consistency in key words and indexing terms as well as major differences among databases. We therefore remain unsure that our search, however extensive, really has accessed all relevant articles.

Another problem limiting the use of research using narrative approaches is that such research often remains on a basic descriptive level, thus not contributing optimally to either new empirical knowledge nor theoretical development as much as might be expected. Kellehear [34] argues this point, as mentioned above, as he addresses the need for more cross-fertilization between related research areas. We also argue the need for more precision in research questions and better use of design in narrative research approaches, including the use of more longitudinal studies to understand how meanings change along a sickness trajectory, to add important new knowledge in a common venture to improve patient care at the end of life.

## References and recommended reading

Papers of particular interest, published within the annual period of review, have been highlighted as:

- of special interest
- of outstanding interest

Additional references related to this topic can also be found in the Current World Literature section in this issue (pp. 215–219).

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