Making Sense of Receiving Palliative Treatment
Its Significance to Palliative Cancer Care Communication and Information Provision

Background: By receiving palliative treatment over time, a growing number of people with advanced gastrointestinal cancer are living longer. An image of palliative care, often existing in the public, as being exclusively for the dying could thus be particularly challenging in relation to patients’ making sense of receiving palliative treatment over time. Objective: The aim was to interpret how patients diagnosed with advanced gastrointestinal cancer make sense of receiving palliative treatment. Methods: A phenomenological life-world approach was chosen. Seven men and 7 women with advanced gastrointestinal cancer receiving palliative treatment were followed up using repeated narrative interviews, which took place at a Swedish oncology clinic. In total, 66 interviews were conducted. The analysis followed hermeneutic principles and was interpreted stepwise. Results: Making sense was revealed as a phenomenon constructed narratively, through patients’ searching for knowledge and understanding, approached by a dialectic pattern of living in wait and in the present, and finally, as a process of human learning through being and becoming, which transforms the experience and results in a changed personal experience. Conclusion: Making sense of receiving palliative treatment is a process of human learning at the end of life, characterized by an ongoing search for knowledge and understanding. To enhance patients’ sense making in this context, professionals need to go beyond “providing information.”
Implications for Practice: The attention of health professionals must be directed at recognizing and enhancing patients’ ways of seeking knowledge to help them make sense of receiving palliative treatment. Person-centered activities need to be developed.

Over the last 2 decades, considerable progress has been made in the therapy of advanced or metastatic gastrointestinal cancer. Current chemotherapy regimens have greatly improved the outcomes of metastatic cancer, and there is even a moderate possibility of a cure for those with colorectal liver metastasis. Probability prognostication of treatment outcome is also advancing, and as a result, an increasing number of people with advanced gastrointestinal cancer are living longer with the help of palliative treatment, that is, treatment aimed at relieving symptoms and improving quality of life. A combination of cancer therapy and palliative care coupled with greater awareness of the rehabilitative and palliative purposes of care is firmly in line with current descriptions of palliative care. However, this approach deviates from the image of palliative care as being exclusively for the dying, thus contributing to the potential difficulty for patients to comprehend and make sense of this experience.

With palliative treatment, people live longer with an uncertain future. This is particularly the case for people who receive palliative treatment over a period of time—up to years with a combination of therapeutic advances and recurrences. On the one hand, receiving palliative treatment suggests incurable conditions and approaching end of life; on the other hand, the actual treatment procedures (eg, infusions and injections) appear to the patient to be almost identical to receiving curative treatment. In this way, making sense of receiving palliative treatment could be particularly challenging. The danger of not making sense could be that the patient remains unaware of the fatal outcome, thus contributing to communicative challenges between patients, significant others, and professionals. In the context of personal handling of palliative treatment, sense making is of special significance for the alleviation and transformation of suffering and is thus fundamental to achieving the overall goal for palliative care.

Sense making is embedded in time and space. We reflect on the past, live in the present, and plan for the future. We make sense of that which is lived through. The sense-making process involves dimensions of emotions, will, memory, beliefs, imaginations, and language. In this way, sense making is both socially and culturally embedded.

Previous research presents making sense of illness as being the result of interrelated emotional and cognitive dimensions focusing on health-related beliefs and explanations, the various actions taken by patients to handle illness, and their motives for doing so. Furthermore, interactive and ongoing processes of sense making, with various explanations for illness, are substantially different from the professionals’ biomedical explanations.

In the case of patients with advanced gastrointestinal cancer, sense making has been described only as a subtheme in the patients’ experience of being diagnosed with advanced colorectal cancer. Interpretive inquiries related to living with gastrointestinal cancer have focused on areas such as being given a diagnosis, recovery from surgery, sense making in illness, surviving treatment, surgical treatment for metastases, alleviation of suffering, and human learning at the end of life. Although we found studies dealing with making sense of illness in relation to women with recurrent breast cancer, patients with a brain tumor and their caregivers, bereaved caregivers, and volunteers, the sense making of patients receiving palliative treatment appears not to have been a focal point. Study in this area would significantly contribute to understanding the impact of the complexities of information provision in palliative cancer care.

Aim

The aim was to interpret how patients diagnosed with advanced gastrointestinal cancer make sense of receiving palliative treatment.

Methods

Making sense is here regarded as a “lived” phenomenon, interwoven with a number of significant aspects that could in part be taken for granted and communicated implicitly. A phenomenological life-world approach was therefore selected for the inquiry. Fieldwork supported by phenomenological thinking was established in which patients were invited to share their stories relating to what they needed to know and understand while receiving palliative treatment. The analytical process was phenomenological hermeneutic and followed the theory of interpretation according to the philosopher Paul Ricoeur.

Participants and Fieldwork

An outpatient oncology unit specializing in advanced gastrointestinal cancer at a university hospital in an urban area of Sweden was chosen, partly because it had an explicit profile of applying palliative care principles and partly because patients were cared for through the curative, adjuvant, and palliative phases. The aim was to include a comparatively homogenous group of patients with advanced gastrointestinal cancer but at the same time present a wide variety of social aspects. Four nurses at the unit were instructed to approach patients of both genders and of all family and socioeconomic situations to ask if they would be willing to participate in the study. The criterion for inclusion was ongoing palliative treatment for advanced gastrointestinal cancer, whereas the criterion for exclusion was inability to take part in conversations.

Fourteen men and women (pseudonyms are used for the participants), all born in Sweden and between the ages of 49
and 79 years (median, 68.5 years; mean, 65 years; Table 1), were included. Most of the participants lived in urban communities with a varying socioeconomic spread, and a few in rural areas. All the participants had children, but only 3 had children (all teenagers) living with them at home. A range of professions were represented in the group, including shop assistant, auxiliary nurse, shipyard worker, transport worker, social worker, teacher, economist, personnel manager, entrepreneur, and performing artist. The majority of the participants had a history of cancer in their families.

Fieldwork comprised narrative interviews and supplementary observations, with the aim of following most of the patients over time in order to create “safe space” between participants and researchers, thus enabling the former to share their experiences, including more delicate issues. Narrative interviews were conducted and varied from 30 to 120 minutes in length (most were approximately 1 hour). With the patients’ informed consent and depending on the progress of the disease, repeated narrative interviews were conducted, varying in number and frequency (Table 2). Although our intention was to follow the participants throughout their palliative treatment, this was possible only for a minority of the participants because of practical reasons (when in need of continuous day and night care, most of the patients were transferred to various home care and hospice organizations). The patients’ disease trajectories from initial diagnosis varied from 2 months to 2 decades. Participants were included between 1 month and 3 years after having received the diagnosis of advanced gastrointestinal cancer and the commencement of palliative treatment. Inclusion of patients was performed during a 1-year period. In total, 66 interviews were carried out over a period of 2½ years, apart from 1 participant (Berit) who was followed up for 5½ years. The participants were followed up between 1 week and 1 year before their deaths with 1 exception, a man (Johan) with colon cancer and liver metastasis who went into remission and survived. The participant (Berit) who had been followed up for 5½ years was diagnosed to be cured after 4 years but had a recurrence half a year later and died 1 month after the last narrative interview. Her shifting trajectory provided new insights over the extended period of her palliative treatment for comparing and contrasting against the shorter and more typical experiences of the other participants. Ethical clearance was obtained from the Ethical Committee in Gothenburg (Ref O437-02, S551-03).

Asking participants for their informed consent for repeat interviews paved the way for rich and diverse data as well as for meeting participants in different settings (Table 2). Each participant met with only 1 researcher—either the first author or the last author (an even split of participants between them)—and the first meeting was always conducted at the outpatient unit. Narrative interviews were conducted in order to open up topics and share stories related to what the participants sought to know and understand in order to handle their everyday life while receiving palliative treatment. The following probes were used in the conversations: what they needed to know and wanted information about, how they sought it, what they asked team members at the clinic about, what they wondered about at home, and what their preferences were regarding information and knowledge. A great deal of effort was made to respond to the participants personally and to demonstrate openness, which involved sensitive

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<th>Table 1 • Description of the Participants</th>
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<th>Table 2 • Interview Frequency and Venue</th>
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questioning, open-mindedness, open-heartedness, and caution with regard to disclosing one’s own preconceptions.35 36

In order to contextualize and facilitate the narrative interviews, the researchers made observations coupled with reflections on their own experience of the encounters and situations and were open as to how these observations and reflections could be understood by the participants.31 In appropriate cases, the actions and episodes observed and the experiences gained were shared with the participants and used to open up further topics for dialogues.

Most of the interviews were audio-recorded, and in a few cases, notes were taken, although always with the patients’ informed consent. In addition, reflective notes were made directly after the interviews, with a focus on both the aim of the research and the shaping of the relationship with the participant. These notes were used in preparation for the next meeting with the participant, which began with an invitation to talk about what they had gone through since the last meeting.

Analysis and Interpretation
Verbatim transcriptions of the narrative interviews were analyzed phenomenological-hermeneutically in 3 interrelated phases, labeled by Ricoeur33 as naive reading, structural analyses, and interpreted whole. The aim of this process is to incorporate an analysis from surface and simplicity to depth and complexity.36,37

The analysis was performed by all 3 authors, and meetings were held regularly during the process. Any points of difference were discussed until agreement was reached, and the analysis started after all the interviews were conducted. The subsequent analyses were performed to disclose layers of meaning, from the obvious to embedded, latent meaning. Because one of the participants (Berit) was followed up more intensively than all the others (Table 2), data (15 interviews) from the first 2½ years for that individual were used together with data from the other participants for the initial analysis. The remaining data from that participant were used for comparison with the preliminary interpretations.

In the naive reading phase, we read the whole narratives from start to finish to develop an initial and general understanding of the phenomenon of interest, that is, making sense of receiving palliative treatment. During our reading, we focused on the world of the narrators and used the reflections that arose as guidance in the structural analysis.

In the structural analyses phase, we examined the narrative structures (first structural analysis), searching for narrative categories such as dramatic units, actions, scenes, and a temporal order of narratives and sequences. Each dramatic unit found was compared, and similar dramatic units were put together. The same procedure was used to find actors, scenes, and temporal orders, after which we performed several analyses guided by the analysis of narrative categories in order to identify themes. Having searched for meanings and actions by processing the data with the computer software NVivo 9 (QSR International, Doncaster, Victoria, Australia), we then read the narratives sentence by sentence and identified and condensed meaning units. These condensed meaning units were subsequently abstracted and labeled, and the process moved on to interpreting the actions taken and their associated meanings (second structural analysis). We then jointly compared the narrative categories and sequences of units of meaning of each participant with the narratives and sequences of others (third structural analysis), all the while trying to discern the directness of their stories on one occasion compared to that of their stories on other occasions and their approaches to sense making. For the results, we chose to present stories that had commonality among the participants, exemplifying any variations and nuances in these.

Finally, for the interpreted whole, we focused on the world of the phenomenon—making sense of receiving palliative treatment. Our gradual distancing from the encounters with the participants to the disclosed meaning structures of the narratives was combined with insight from explicit preunderstanding of selected literature that we considered relevant and that we subjected to critical reflection. By moving between the whole and its parts, the aim was to create a deep and more comprehensive understanding of the meanings revealed during the structural analyses.

Maintaining Rigor
Accuracy throughout the study was ensured mainly by considering 4 principles suggested by Thorne.39 First, epistemological integrity was secured in the research process by making decisions in line with phenomenological knowledge interests that were considered to be significant to clinical knowledge interests in palliative care, that is, informative for practitioners. Second, the representative credibility of the study was mainly dependent on the sampling principles and the nature of the fieldwork. A major reason for limiting the fieldwork to one clinic was to establish familiarity between the researchers and the clinicians in order to facilitate observations and thus establish trust between the researchers and the participants.31 An analytical logic has been promoted by explicating the analytical decision-making process in relation to the knowledge interest of the study.30 The overarching interpretive structure of naive reading, structural analysis, and comprehensive understanding acted as a useful tool during the analysis to localize the interpretive foci of the world of the narrators, the narratives, and the phenomenon.30 During the analysis and interpretation of the narratives, we paid particular attention to the ways we as researchers co-constructed the participants’ accounts and to indications of certain meanings across interview time points and participants. Finally, we promoted interpretive authority by revealing knowledge about intertwined existential and experiential knowing as related by the participants. Illustrative quotations from the interviews are included to help the reader to assess consistency between our interpretations and the data examples.

Results
Naive Reading
The participants presented narratives that revealed uncertainty regarding their changed and still-changing life situations
following short- and long-term palliative treatment. Furthermore, their uncertainties regarding how to make sense of receiving palliative treatment revealed aspects of how they were coping with everyday life. The participants narratives also contained descriptions of activities and ways of seeking knowledge and understanding related to receiving palliative treatment, which appeared to be shaped by the intervals between the chemotherapy, mostly every second week, as well as check-ups and tests, such as computed tomographic scans every third month. There were also descriptions of a varying need for knowledge and understanding and related questions. This was presented along a continuum, from a desire to know as much as possible to being confident about what is known and no desire to understand anything further. The narratives included descriptions of how the participants uncertainty was dealt with by the professionals and others, in addition to their standpoints and foci while making sense of receiving palliative treatment. The associated meanings seemed to be embedded in the activities undertaken and thus appeared to show that making sense of receiving palliative treatment involved several layers of meaning and actions.

First Structural Analysis: Narrative Categories

The most common figures included in narratives of making sense of receiving palliative treatment were the person in question, family members, physicians, nurses, care providers, fellow patients, friends, and professionals. The most common venues were participants homes, as well as hospital and consulting rooms. The dramatic units focused on waiting, being in need, hoping, examinations, observing, reflecting, listening, asking questions, and seeking. These mainly occurred in a sequential order, from the time when the cancer was suspected by the individual to the present and the future. The analyses of narrative categories indicated that advanced gastrointestinal cancer patients coped with everyday life through a variety of activities in order to make sense of receiving palliative treatment. The use of activities seemed to validate the naive reading and indicated a need to interpret further the patients search for knowledge and understanding, which in turn led to interpreting the narrators search for enhanced hopefulness in their uncertain life situation.

Second Structural Analysis: Patients Search for Knowledge and Understanding

Two areas of activity were revealed: the need for knowledge and understanding and ways of seeking knowledge and understanding.

IN NEED OF KNOWLEDGE AND UNDERSTANDING

To facilitate sense making in relation to their palliative treatment, patients spoke of their need for knowledge and understanding in order to cope with everyday life. This was characterized by illness, treatment, and related decision making, as exemplified below by a woman who had been receiving palliative treatment for just over a year:

Inez: I want to know how things stand.

Researcher: So you want to know what the situation is?
Inez: Yes, exactly. Because, otherwise I cant make any assessments. Like the previous time I said no to radiation. Ive done it this time, too, because I weigh matters up very carefully all the time. I need really concrete messages about how things are looking, what the assessments are, and what the medical profession says. Then, when the physicians have said their piece, I can make my decision. Do I agree with it or not?

The participants needs were partly related to a need for facts, implying unbiased sources. From patient narratives, one also sees his/her need for hope implied in part by a reinterpretation of knowledge and information in relation to his/her preferences and beliefs. The facts would have to be neutral and could come from any unbiased source or individual. Knowledge instilling hope requires knowledge of the patient as a person, including aspects such as biography, beliefs, family situation, and existential interpretation of the disease and illness. Participants spoke about tumor activity; prognostic prospects; symptoms; medical and nonmedical alternatives for cancer treatment and symptom relief, including complementary therapies; strength and weakness; and aspects related to illness, worry, and distress. Need for knowledge thus ranged from queries and worries related to disease, treatment, and illness, to thoughts about different aspects of life. Existential questions arose such as "How much time do I have?" and "Should I hide myself under a blanket and wait for death, or should I fight for my life?" Some of the participants stated that thoughts of this nature, coupled with consternation at their not experiencing any of the radiation adverse effects mentioned in the information, evoked questions such as "Why can my body deal with the side effects?"

WAYS OF SEEKING KNOWLEDGE AND UNDERSTANDING

Two major ways of seeking knowledge and understanding in order to make sense of receiving palliative treatment were related: consulting oneself and consulting others. The patients consulted themselves by performing their own tests and self-examinations and through personal reflection. The tests ranged from obvious evaluations of self-care abilities, to inventing, performing, and obtaining knowledge from different self-examinations of the body, such as in cases where prescribed symptoms therapies did not reduce distress. Self-examination included assessments of the body, which included beating, knocking, touching, and observing it. Reflection meant seeking knowledge and understanding by exploring situations and by pondering, assessing, and comparing. This could involve deliberating on the professionals treatment suggestions and the results from examinations and tests before deciding whether to agree to the treatment offered.

Patients spoke about consulting others by means of listening and talking to professional healthcare providers and fellow patients and by turning to the media. Some participants emphasized the importance of not limiting themselves to approaching professionals because of the uncertainties related to their prognosis. As a participant stated: "As a patient, I needed to understand that physicians didn't have ready answers. They could not promise me..."
that I would live for 1, 2, or 20 years.” Some, but not all, of the participants emphasized listening to fellow patients’ experiences, reasons including “They are the ones who know best about what’s coming next” and “It was easier to talk about tumors with fellow patients than with nurses.” There were also situations when patients spoke of being careful about “loading themselves with facts about cancer.” However, concerns were also raised about consulting fellow patients, as demonstrated in the following example of a woman who had received palliative treatment for 2 years:

Berit: I got this wake-up call. I met a woman when I was there [at the clinic], 2 times ago. Well, it was a month ago, more than a month ago. She was much younger than me, and she didn’t look, I mean, look cancer sick. With the hair and all that. But she had been on treatment for 3 years. And she’s had blood transfusions because of tiredness. I thought, heaven help me. I’m not there yet. I brought it up with my nurse later on. She said it can be for better or worse that you meet [fellow patients in the same situation].

The participants emphasized the need to observe professionals’ body language as it could reveal hidden aspects of information. Participants told of turning to the media (TV and the Internet) when searching for knowledge, especially in the desire to know that new treatment methods would soon be available to patients with advanced gastrointestinal cancer.

Third Structural Analysis: Dialectics of Living in Wait and in the Present

In the narratives related to making sense of receiving palliative treatment, the above meaning structures directed us to an additional meaning structure, which we interpreted as approaches adopted by the participants when sharing their experiences. These approaches were taken more or less as a given and are implicit in the narratives. Opposing narratives were put together in order to identify possible patterns, and thus approaches of living in wait and living in the present became clear. The relationship between the two appeared dialectic: living in wait included a longing for memories of living in the present, and living in the present involved to a varying degree threats and memories of living in wait.

Waiting limited available time and space. Thus, preoccupied with waiting, participants spoke of having no room to do anything else. Living in the present, on the other hand, was about extending time and space; having room to think about the past, present, and/or future in creative ways; and embracing positive sense-making ways and was thus more preferable to living restricted by the threat of death. Moreover, the dialectic pattern seemed to be related to beliefs in survival, cure, and well-being inasmuch as patients persisted in waiting for a cure and aspiring to well-being despite an implicit or explicit awareness of their severe illness and mortality. Belief in a cure was said to be stronger and more prominent than belief in well-being. Believing in a cure thus became a means of achieving well-being. In narratives that revealed a clearer belief in the attainability of well-being, the prospects of a cure or belief in a cure became less significant.

Living in wait involved waiting for various test results; waiting for the tumors to shrink, disappear, or recur; and ultimately waiting for death. This wait was marked by the intervals between chemotherapy and check-ups with the consultants, which created a rhythm of living in wait in cycles of between 2 weeks and 3 months. The chemotherapy routine thus became a symbol of hopeful waiting, postponing the prospects of death. This is illustrated in the example below of a woman who had received palliative treatment every second week for 2 years:

Anna: [First name of the primary nurse] says I can take a break for a week if I want to. But I don’t want to. Because then I dream about getting worse. Now, the consultant has said that I won’t have this treatment next week. Instead, I’m going to have it every fourth week.

Researcher: What do you think about that?

Anna: Well, both yes and no. I do dream that taking a break will make me worse.

Most of the participants spoke of waiting during the first 3 to 7 days after chemotherapy for the dizziness, fatigue, and in some cases nausea to decrease. They could then live as they wished until the day before the next chemotherapy. Such “free” intervals sometimes disappeared while waiting for the next computed tomographic scan to be scheduled or performed, or for the next meeting with the consultant. The waiting is exemplified in the following story of a woman who had undergone 3 years of palliative treatment for multiple metastases just over 1½ years after inclusion in the study:

Berit: Nowadays I come here [to the clinic for chemotherapy] with a lump in my stomach. I didn’t do that in the beginning, because then I expected treatment even after 3 months and [for treatment] to work continuously. Now I have come to terms with it. As long as the disease is kept at bay, then I come here every 14 days and have my treatment. It’s a way of life. But I want to do so many more things, you know. I’ve scheduled my life 100% around my chemotherapy treatment. I really have.

Researcher: So you’ve arranged your life to fit in?

Berit: That’s what I’ve done. Monday, Tuesday, Wednesday, that’s when I can meet people for sure and actually do things in the evenings. But I never make any plans for Thursdays and Fridays.

For the participants, living in the present thus involved prioritizing their interests, either on a large scale or simply by having a favorite drink; prioritizing time with family, friends, and/or groups; and putting their sociofinancial situations in order. Many participants frequently spoke about living in wait, whereas a few spoke occasionally but clearly about living in the present. Participants also spoke of the expectations of significant others in regard to the shifts between living in wait and living in the present. These expectations could grate with the participants’ own feelings, as illustrated below by a woman 2 months after recurrence and 6 months before her death:

Daisy: I’ve been wondering about whether to buy a new chaise lounge or not.

Researcher: So you’re thinking about it?
Daisy: So then my mother says, hey you’d better wait and see how things turn out. But how do I know? Why shouldn’t I buy a couch right now? Why should I wait? I mean, even if I wait a year and everything’s fine, I could easily come down with it again.

Interpreted Whole

The interpretation can now be taken one step further. Making sense of receiving palliative treatment related to everyday life with advanced gastrointestinal cancer was interpreted as an ongoing activity involving a search for knowledge and understanding combined with dialectic approaches of living in wait and living in the present, based on influencing beliefs (Figure). Patients emphasized the need for having factual knowledge as well as facts related to their specific personal situation in order to instill hope, and the dialectic movement between living in wait and living in the present was significant in their approach to sense making. For the patients in this context, waiting was closely related to a belief in a cure for their cancer despite awareness of their own mortality, and living in the present was related to belief in the possibility of a life characterized by well-being, despite progressing, incurable cancer. Within the framework of these approaches to the situation, patients pursued different activities that helped them to deal with and enhance hopefulness in their uncertain life situations. A patient’s attitude to tensions between health beliefs related to cure and well-being will thus have implications for how they manage their treatment and care in everyday life, for example, by postponing activities or living as normal and focusing flexibly on the present.

The experience of making sense of receiving palliative treatment implies a process of human learning, a process where knowledge and understanding are constantly challenged and reformulated, and where dialectics between living in wait and in the present could be interpreted as an interplay between being and becoming.40 Here we allude to the notion of human learning to Jarvis’40 theory: “the combination of processes whereby the whole person—body (generic, physical, and biological) and mind (knowledge, skills, attitudes, values, emotions, beliefs, and senses)—experiences a social situation, the perceived content of which is then transformed cognitively, emotively, or practically (or through any combination) and integrated into the person’s individual biography, resulting in a changed (or more experienced) person.”40 A person receiving palliative treatment thus transforms the experience, and the sense making transforms the person, resulting in a changed personal experience. Transformation means that bodily experienced sensations need to be transformed into mental meanings through which we explain our personal experience,40 which also involves an identity-shaping process.

Discussion

Making sense of receiving palliative treatments for patients diagnosed with advanced gastrointestinal cancer was interpreted phenomenological-hermeneutically, based on prospective data from 14 men and women recruited from an outpatient oncology unit at a Swedish university hospital. Interpreted through Jarvis’40 work, our results indicate that patients make sense of receiving palliative treatment through a human learning process in which knowledge-searching activities are combined with knowledge-searching approaches characterized by dialectics between living in wait and living in the present. Furthermore, the knowledge searching is based on influencing beliefs; waiting is related to belief in a cure despite awareness of own mortality, and living in the present is related to a life where well-being is attainable despite the progressing and incurable character of the disease. Some individuals try to live life as genuinely as possible despite advanced cancer and do the things they want; some are more focused on the circumstances, such as the next consultation or the next chemotherapy treatment. These people seem to live their life waiting for something—waiting for a time. Experience of time is of great significance to patients with advanced cancer. Time is both lived and chronological. Living in wait and in the present are 2 different approaches and can presumably be seen as 2 different ways of approaching sense making in the context of palliative care.

Sense making could be regarded as a key process for patients receiving palliative treatments, coshaped by other processes reported to be of central significance such as suffering.41 The disclosed dialectics between living in wait and in the present are revealed as being significant to the patients’ approaches to the situation, whereby living in wait is highly restrictive, whereas living in the present is more unrestricted. Living in the present does not imply a preoccupation with the subject of death, however. Rather, it means individuals feel more at liberty to choose the occasions and the extent to which they ponder and speak about it. From the perspective of suffering,42 this means time to suffer emotionally, which might make way for sense making to transform suffering into alleviation.43 Being preoccupied by waiting will push the sufferer into enduring the situation, whereas a focus on the present will delimit the scope for considering the past and the future. In this way, sense making implies the inclusion of existential and spiritual dimensions.43 The possibility to freely
shift between living in wait and in the present for patients receiving palliative treatments may be highly influential in patients’ suffering and consolation, which in turn implies influence on inner life processes at the end of life, such as reviewing one’s biography and one’s thoughts about life and death, as described by McSherry. These shifts are similar to the transformative process of adjusting to persisting life-threatening breast cancer in the grounded theory study by Kenne-Sarenmalm and coworkers, in which making sense of living under the shadow of death was characterized by a personal transition process of sense making while adjusting to impending death. Here, sense-making theory comprised 3 phases: confronting shifting expectations and awareness, struggling and easing distress, and transcending with the creation of wellness. Struggling and easing distress can be likened to strained movements between living in wait and living in the present, and the creation of wellness can be likened to living in the present. These shifts can also be likened to the opposing mode of sense making as a means of achieving emotional coherence, which Ramfelt and coworkers described as unified embodiment and dichotomized embodiment. Making sense thus has an embodied nature, and reducing symptom and existential distress may be essential in enabling patients to make sense. This underlines the fact that the inability to move freely in the dialectic pattern may not only obstruct patients’ learning but also increase their suffering. However, being forced to abandon a belief in a cure might throw the patient into unendurable suffering.

Limitations

Rich data were generated from fieldwork with narrative interviews and supplementary observations followed by a rigorous analysis. However, some major limitations need to be mentioned. Data came from a single hospital and a single unit, from a culturally homogeneous sample, using a preset number of participants. Further data analysis was performed after finalizing the fieldwork, which did not permit determination of redundancy. Thus, results may differ in other settings.

Conclusion

The study interpreted making sense of receiving palliative treatment for advanced gastrointestinal cancer as a process of human learning at end of life, characterized by the ongoing activity of searching for knowledge and understanding combined with approaches taken as dialectic of living in wait and living in the present. Knowledge searching was found to be based on influencing beliefs: a belief in a cure for the cancer despite awareness of own mortality and a belief in the possibility that well-being was attainable despite progressing and incurable cancer. A sense-making perspective in this context means that we must go a step beyond just “providing information.” In order to facilitate sense making in terms of a learning process, person-centered communication in palliative care is required.

Implications for Practice

Patients struggle with existential distress, and their need for knowledge and understanding may be intertwined with their suffering at the end of life. Special attention to recognizing and enhancing patients’ diverse means of knowledge seeking may be necessary in order to support them in making sense of receiving palliative treatment and in considering how experiential and existential dimensions of human learning are involved. Our results demonstrate that when knowledge from professionals is contextualized to the individual patient as a person—related, for example, to the patient’s biography, beliefs, values, and emotions or their existential interpretation of the situation and other expressions for person-centered care—making sense is facilitated. As knowledge needs to be contextualized to patients as individuals, we question the relevance of considering patients in need of “information provision” on several grounds. To start with, arbitrary information provision masks previously reported variations in type, amount, and sources of knowledge in patients’ information-seeking behavior. It would therefore be necessary to ascertain patients’ information needs by monitoring such behavior and tailoring information provision thereafter. Moreover, information provision masks the intersubjective and co-constructive character of enabling knowledge seeking and understanding. The information provided needs to be interpreted by the patient in a sense-making and learning process. In palliative care, we need to pay special attention to the ways in which patients become vulnerable, which consequently makes them dependent on how professionals provide the prerequisites for their understanding and sense making through the various aspects of communication—positioning, intonation, choice of terms and expressions, ways of communicating, and so on. For these reasons, enabling patients’ knowledge seeking is linked to enabling their preparedness, which can be facilitated through professionals’ “following” and “allowing themselves to be followed.” In this way, the ethical principle of autonomy needs to be viewed and reconceptualized as relational autonomy. For patients receiving palliative treatment, the conflict between living in wait and living in the present will be of particular significance to preserving the person’s dignity.

Instilling hope for the future without giving the impression a cure may be possible when there is none, and disclosing such bad news sensitively is certainly a major challenge in palliative care. Inappropriate balancing of beliefs may put the patients’ dignity at risk, and sticking to a belief in a cure might obstruct patients, and by extension their families, in making sense of receiving palliative treatment. Here, it appears to be particularly important that palliative teams and clinics critically shed light on their habitual discourse patterns and seek practices to enhance open communication. Clinical supervision of palliative team members might be especially useful, and intervention studies pertaining to the effectiveness of person-centered information and communication are needed.

Because making sense of receiving palliative treatment involves talking to other people about experiences and in doing so developing intersubjective meanings, special consideration should
be given to ways of developing opportunities for patients to share accounts. In the traditional hospice model, this is facilitated by day-care units. However, there is a need in this respect to develop and evaluate supportive activities in palliative care.

References


