



Losing Health Symbols Because of Nutrition-Related Problems in Advanced Cancer

An Interpretative Phenomenological Analysis

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Cancer and nutrition-related problems are extremely distressing events and disturb functioning and daily life. It is recognized that the effects of stressors challenging well-being are mediated by the meaning attached to these stressors. As nutrition-related problems are often being experienced within couples, it is also important to gain understanding of a partner's interpretation of complaints and whether it coincides with that of the patient. To explore the meaning attached to nutrition-related problems, a qualitative approach was followed. Seven couples, each composed of a patient with cancer and his/her cohabiting life partner, participated. Data were collected through in-depth interviews and analyzed by an interpretative phenomenological approach. Nutrition-related problems among patients with advanced cancer are mostly perceived as destroying health and leading to loss of physical, psychological, and social health symbols. Because the meaning patients and their partners attach to nutrition-related problems is individual and dynamic, it is necessary to devote special attention to the issues on different occasions. The study findings can assist nurses and other professional caregivers in providing psychological support for couples confronted with nutrition-related problems in advanced cancer. It is important to take into account the meaning patients and partners attach to these nutrition-related problems.

KEY WORDS

advanced cancer, interpretative phenomenological analysis, meaning, nutrition-related problems, primary care

Most patients with advanced cancer are confronted with severe nutrition-related problems (NRPs), for example, taste alterations, anorexia, dysphagia, unintended weight loss, diarrhea, or constipation.^{1,2} These problems may add to the impact of symptoms and complaints due to the disease. This study takes an explorative stance and seeks to describe patients and their partners' meaning attached to NRPs.

Eating and nutrition are indispensable to satisfy the basic needs, to fuel the body, and to remain physically healthy. However, the inherent psychosocial function of cooking and eating seems of much more importance for people's well-being and quality of life.³ People come together to eat and drink, celebrations are associated with tasty food and drinks, and people take care of each other by providing meals. Thus, food and eating are assigned a symbolic meaning.⁴⁻⁶ Symbols are a type of representation that point to a reality beyond themselves. As such, providing food is associated with taking care and being connected with others,^{4,7} and healthy eating habits have become symbols of healthy living.⁸ Moreover, to some extent, food and eating are related to a person's identity as people describe themselves as "a healthy eater," "a picky eater," and so forth.^{8,9}

At some point during their disease trajectory, most patients with advanced cancer experience eating as a stressful event, which differs profoundly from the expectations of eating in common life and, as such, causing a discrepancy between the appraisal of eating and the global beliefs of how eating should be.¹⁰⁻¹² The meaning-making model is a process in which people attempt to reduce this discrepancy between the appraisal of an event and the global beliefs.¹³

When people are challenged by negative life experiences, for example, NRPs, they often attempt to maintain normality or create a new reality through a search for meaning related to the negative experience.^{14,15} Finding

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positive meaning in challenging experiences has been shown to increase well-being and to enhance resilience and distress tolerance.¹⁴

According to the “Transactional Model of Stress and Coping” by Lazarus and Folkman,¹⁶ the outcomes of stressors endangering well-being are mediated by two interrelated processes: a primary appraisal, which is a process to which the person makes meaning of a stressor, and a secondary appraisal to which the person evaluates what could be done to overcome the stressor. In the same line, considering Leventhal et al,¹⁷ “The Common-Sense Model of Self-Regulation,” somatic sensations that deviate from normal function, for example, NRPs, as well as an observation of illness or those problems, in others, activate the individual’s memories and former experiences and leads to attributing a meaning to the threat. Subsequently, an action plan to overcome the threat is induced, self-management skills can be stimulated, and eventually coping mechanisms are induced.¹⁷ Central to both theories is the idea that meaning making is a crucial mediating process between the experience of a stressful event and how one copes with it. According to differences in meaning, coping may vary, as well as the effect of the stressor on one’s functioning. In summary, giving meaning to an experience could enhance one’s relationship with the existential dimension and the awareness of what is compromised in how one experiences his/her existence and consequently can have a substantial influence on the effects the experience has on people’s lives.

There is substantial evidence of the experience and psychosocial impact of weight loss and anorexia in patients with cancer cachexia syndrome and their caregivers.^{7,11,12,18,19} However, evidence about the meaning patients and caregivers attach to NRPs in advanced cancer and evidence about what happens with the symbolic meaning of food and eating when people should deal with severe NRPs in cancer are limited. Some studies report that, when eating is hampered in palliative patients or in patients having received radiation treatment of head and neck cancer, the meanings attributed to food and eating are associated with physical, psychosocial, and existential challenges and losses.^{6,20,21}

From research to date, it would seem that weight loss and anorexia are more problematic for the caregiver than for the patient.^{7,18,19,22} However, it is still unclear whether there is similarity in the meaning patients and their partners attach to NRPs in advanced cancer and whether the meaning attributed to an NRP can change in the course of the illness trajectory.

Nutrition-related problems in advanced cancer often become a source of frustration for professional caregivers.^{22,23} When patients are asked to nominate a health care professional involved in their care, they usually choose a nurse experienced in palliative care.²⁴ The nurses regard

it as their duty to alleviate the burden induced by eating-related problems and often feel uncertain about how to help.^{22,23} A better understanding and more insight in the appraisal of NRPs and the attached meaning to these health threatening issues can support nurses and other health care professionals in providing psychosocial assistance and in increasing self-management skills in couples facing NRPs in advanced cancer. Therefore, this study is guided by the following research question: “What meaning do patients and partners attribute to NRPs arising in advanced cancer?”

METHODS

As this study focuses on the meaning patients and family caregivers attribute to the NRPs, as a lived experience, interpretative phenomenological analysis (IPA) seemed most suitable for the current research inquiry.^{25,26} The participants’ group was in line with IPA’s recommended sample because it was a small, homogeneous group sharing a common life phenomenon.^{25,26} Small sample sizes are highly congruent with IPA studies’ methodological emphasis: the in-depth analysis of a shared aspect of lived experience focused on the particular rather than the universal.²⁵ The data were analyzed line by line and iterative with constant movement between the different stages leading to an exploitation of the full potential of the data while retaining the integrity of each participant’s story. The emphasis was on teamwork, enhancing the chance to get rich, creative insights in the phenomenon from different points of view.

Participants

Seven couples, comprising of a patient with advanced cancer experiencing NRPs and his/her cohabiting life partner, have been selected by purposive sampling. General practitioners and the chief dietician of a Belgian hospital were asked to identify and contact candidate participants who met the following inclusion criteria: couples comprising an adult with advanced cancer experiencing NRPs and his/her cohabiting partner. The selecting general practitioner or dietician denoted the partner as the patient’s principal family caregiver. The participants were residents in Flanders and could communicate in Dutch. Patients and caregivers diagnosed with dementia were excluded.

Data Collection

The couples were interviewed between November 2014 and January 2015.

A semistructured interview guide was developed, pilot tested, discussed, and adapted. Some basic training in qualitative interviewing was provided to the interviewer by the last author. After the second interview, the interview guide was critically revised by the first, third, and supervising



authors. The emphasis of the interview guide was to encourage the participants to provide a narrative account of their experience by posing open and expansive questions such as “What did this mean to you?”, “How did you feel about that?”, “How did you experience that?”, and “Could you tell me more about that?”. The questions were repeated for all NRPs mentioned by either the patient or the partner. The interviewer gave particular attention to encouraging both the patient and the partner to recount their experience.

To facilitate disclosure of interactions between both members of the couple, the patient and his/her partner were interviewed concurrently. The duration of the interviews was between 45 minutes and 1 hour. All patients were cared for at home.

The interviews were audio recorded and transcribed verbatim by the interviewing researcher. Field notes were made during and after each interview to increase validity of the findings.

Data Analysis

The preparation of the coding process started with a thorough reading and rereading of the interviews by all four members of the research team until a holistic understanding of the participant’s experience was obtained. Subsequently, a narrative report for each interview that mirrors the key storylines in answer to the research question was written down by the first author. During the first team meeting, the narratives were discussed. In the next step, all members of the team analyzed the data independently. The data were analyzed line by line and commented on descriptively (staying close to the words of the participant), linguistic (focusing on the specific use of language) and conceptual, (situated on a more interrogative and interpretative level). Conceptual schemes were developed from each interview, and all emerging concepts were listed. Concepts emerging from the first interview were used to read the next transcript. Additional concepts were added to the former list, and the first interview was reread searching for evidence for the new themes. This process was repeated for each interview. In addition, the first author discussed the concepts of the richest interview with the supervisor of the study to fine-tune the level of interpretation. All conceptual schemes were compared, discussed, and optimized within the research team. Overlapping or vague concepts were removed from the concept list by mutual consensus, and each concept was well delineated and defined.

The actual coding process started with the introduction of the resulting concept list as preliminary codes in NVivo 11. During the next stage of the process, all relevant fragments of the available interviews were linked to the appropriate codes and there was a careful exploration of all citations associated with the code. In this final stage, a

constant comparison method was used to continually check, discuss, and develop insights in the studied phenomenon.

This iterative, in-case, and across-case analysis method, based on teamwork, adds to the reliability and validity of the study results.

Ethics

Ethical approval was provided by the Ethical Commission of University Hospitals Leuven on September 8, 2014. The study number is B322201420991, with reference number S56553. Before the start of each interview, written informed consent was obtained from all participants.

RESULTS

All patients were between 62 and 79 years old, with an average age of 67 years. Four female and three male patients were interviewed. All the couples were heterosexual, making three female and four male caregiving partners. Five patients had gastrointestinal cancer: colon cancer, gastric cancer, pancreatic cancer, or esophageal cancer. One patient had breast cancer, and one was diagnosed with oropharyngeal cancer. All patients were confronted with at least four of the following NRPs: anorexia, weakness, dysphagia, steatorrhea, nausea, weight loss, taste alterations, sticky mucus, fatigue, diarrhea, dry mouth, early satiety, reflux, and vomiting.

Meaning Attributed to NRPs in Advanced Cancer

Most patients and caregivers described NRPs in advanced cancer as a tremendous threat of health status and as a loss of all health symbols food and eating use to point to (1) loss of physical health symbols, (2) loss of psychological health symbols, and (3) loss of social health symbols. Nonetheless, some patients did not attribute any existential meaning at all to NRPs and described them as only objective facts.

Loss of Physical Health Symbols

Loss of Life: Confrontation With Death

All patient participants experienced involuntary weight loss. Patients often talked about the NRP as an objective fact or as something that did not really matter. For their partners, however, weight loss was regarded as one of the most life-threatening cancer signs and often gave rise to anxiety. Thus, the partners appraised weight loss as a loss of physical health symbols, inevitably leading to physical weakness, fading away, and, eventually, death.

I weighted 88 kg (194 lb) and I've lost 20 kg (44 lb) in 1,5 year. Now, my weight is 68 kg (149 lb). That's in the run of 2 years and just paying attention of what we eat. (a patient about her weight loss)



I wished that I had lost 10 kg (22 lb) too. No, but, I used to think that he was too heavy and now, everything has gone. It's even so that you can see his skin hanging down. (a partner)

I feel pity for him, of course. And when he's naked, he resembles exactly people living in a concentration camp. (another partner about her husband's weight loss)

Loss of the Opportunity to Stay Alive by Losing the Ability to Eat

Patients often talked about eating or taking up calories as a condition to stay alive. The ability to eat fluctuated significantly for some patients and seemed to be an important determinant of hope: if one can eat, one will not die and there is hope to stay alive.

At the start, I didn't taste anything. The only thing I was tasting, was the chemo. That's not a pleasant feeling because in that case, you have to eat as a little child because you have to eat something somehow. (a patient)

They gave me some bags with energy-enriched feeding. For that time, I didn't eat but I got enough calories. That's what really got me through this, you know. (another patient told about how enteral feeding was keeping her alive)

Loss of Psychological Health Symbols

Loss of Emotions Versus Provocation of Strong Emotions

Nutrition-related problems were pointed to as a psychological burden with an important influence on the patient's mood, often evoking intense emotions such as feelings of despair and incomprehension or feeling miserable. On the contrary, once NRPs were arising, for example, once eating was hampered or patients could no longer leave the house because of a severe NRP, some patients approached the problems very rationally without expression of emotions. The only way one of the patients could disclose emotions was by talking about food and eating. Once she could not eat anymore, she had no vocabulary left to communicate about emotions.

On the question "What did it mean to you, no longer being able to eat?", she answered: "Actually nothing. I mean, I was laying here just like this and for that moment, I didn't have time to be sick."

On the question "How did you feel about no longer being able to go shopping?", a patient answered: "Well, not that much, actually."

On the contrary, another patient expressed how strongly nausea influenced his mood:

I feel really unhappy with that. That's because of the chemo now, that's an after-effect. And why I do feel like this now and I didn't in the past, I don't know. I'm not happy with that. But yes, you see, I have to go forward with it. (...)Yes, I feel very unhappy with that.

Loss of Control

The couples also talked about NRPs as a loss of control. Because symptoms could not be kept under control, health status could not be influenced, and both patients and their partners became overwhelmed by feelings of helplessness and confusion.

I used to weigh 78 kg (171 lb) and the last time they've put me on the scale, it was 74 kg (163 lb). Now I'm eating so much, so I don't understand it. (a patient)

Yes, however, now with the disease, he has difficulties to swallow, which frustrates me because I can't do anything about it. And then I see him coughing as well. Then I take my plate and go sit in the couch. (a partner)

Loss of Identity

Some patients related their identity to the way they used to eat, talking about themselves as being a good eater, a healthy eater, and so forth. For those patients, identity was threatened when eating was hampered.

No, no, taking everything in account, I'm able to eat well. Although the portions are rather small, but I finish my plates. I've always been a good eater. (a patient)

Loss of Social Health Symbols

Loss of Communication

Communication is paramount in social interactions and relationships. From these data, however, it seemed that NRPs often impeded communication between the partners. A partner noticed her husband having changed eating habits without having them discussed. She can only guess why this happened.

He eats less. His eating pattern has changed a bit. He never used to eat sweet things and now, he sometimes eats ice-cream, a lot of jam. Maybe that's easier? He eats less meat, too.

Some patients tried to hide their NRPs for the partner and came to disclosure during the interview.

Now, its so that I have, you [husband] don't know this but, yesterday morning, I was eating and it felt like it all got stuck. The juice came out, not the rest.



Loss of Daily Couple Life

Both patients and caregivers talked about activities such as preparing meals, going to the supermarket, and dining together being embedded in daily life and routines. Nutrition-related problems hampered the couples' routines and daily life.

A partner: "When I was going to the groceries, I used to bring food for 3 days, but not anymore. Formerly, that was easier. The patient: "Now, every day I want to eat something different."

Formerly, we did it together [shopping]. That was before I got sick. But now that I'm sick, he has to do it all by himself. (a patient)

Loss of Social Activities

Early satiety, dysphagia, steatorrhea, and nausea were all symptoms associated with a loss of social activities. Patients felt ashamed because they could not finish their plate or because of the smell of their stool and stopped attending social gatherings or no longer visited restaurants.

We don't go out often, but that's not more or less than it used to be. If we do so, I don't want to go on Thursday, Friday or Saturday because than I should recover somewhat. (a patient)

Now and then, we went on a gastronomic weekend. Now, that's another thing that's no longer possible because I can't eat that much, anymore. (another patient)

Loss of Carelessness: NRP as a Punishment for the Partner

Patients often felt embarrassed because their partner's life was influenced by their NRPs. They tried to push the partner to attend social activities. The partner, on the contrary, mostly accepted the situation and did not feel punished.

I then think it should be hard for him because then he's punished too, I say then. And then I say: 'then you can go,' but he doesn't do that either. (a patient)

Dynamics in Meaning Attributed to NRPs

Although the couples were interviewed only at one moment in time, they talked about their experience of NRPs on different stages during the illness trajectory. During the interviews, it became obvious that the meaning one couple or one member of the couple attributed to one specific NRP often changed over the illness trajectory. This was very clear in the case of one of the couples, confronted with dysphagia. At first, neither the patient nor her partner attributed any existential meaning to this NRP. They talked about it as if it was simply an objective fact.

During the illness trajectory, the meaning of this NRP seemed to have changed to a loss of physical health symbols and eventually to a loss of social health symbols.

Now, at the last consultation, it became more difficult to swallow, bit by bit. At first, it wasn't alarming. At a given moment, food stuck. Sometimes it took 10 to 15 minutes before it passed. Then she had to sip and after that she could continue her meal. (the partner)

"On one hand, if they could control or stabilize the tumor now, which should allow her to eat normally again. Maybe at first ground again." The patient: "Bit by bit building it up again, if that should be possible." (the partner)

I really felt sorry for that. Something is missing. You're invited somewhere, but you can't go because you can't eat. (the partner)

Incongruence in Meaning of NRPs

From these data, an incongruence in the meaning patients and partners attributed to NRPs could be revealed. Partners often perceived NRPs as a loss of physical health and a confrontation with pending death, whereas patients perceived the same NRPs as rather a loss of social or psychological health or talked about the NRPs as if they were only objective facts. One couple was confronted with steatorrhea associated with a heavy smelling stool. Although the patient did not attach any existential meaning to that problem and only mentioned it, the partner considered it a threat for her social life.

There only are some smell-problems when she used the toilet and then I think that, if she's going out, she won't dare to use the toilet soon. Sometimes, it's really... That's the only thing that's bothering me. (the partner)

Sometimes when I fart, it smells awful too. I didn't have that before. (the patient)

DISCUSSION

Principal Findings

The findings from this study reveal new insights into the meaning patients and their partners attach to NRPs in advanced cancer. They both appraise the problem individually. Although most NRPs confront the couple with a loss of physical, psychological, or social health symbols, there is not always congruency in the attributed meaning between patients and their partners. Moreover, the meaning that one or both members of the couple attach to one specific NRP can change during the illness trajectory.



What Is Already Known and What This Study Adds

The findings about the meaning attached to NRPs correlate with the conclusions of Wallin et al,²¹ stating that eating deficiencies in palliative patients are related to psychosocial and existential challenges leading to withdrawal from social gatherings and “mental shutdown.”

In a recent study, Hopkinson⁷ described eating and food representing symbols of a healthy living connecting us to others. Weight- and eating-related problems were consequently considered as disruptions of those food connections. These findings can be affirmed because the participants experienced NRPs as a loss of all health symbols. This study showed that those findings can also be expanded to other NRPs, not immediately linked to cancer cachexia syndrome, for example, diarrhea, constipation, weakness, and fatigue. Nevertheless, the interdependency of weight- and eating-related distress in couples could not be subscribed because, in this study, there often was no congruency in meaning attached to NRPs between both members of the couple.

This lack of congruency underpins the statement of Fletcher et al²⁷ that appraisals are unique to individuals and that similar stressors may elicit different meanings and the findings of Hopkinson⁷ and Amano et al²⁸ stating that there is a disparity in anxiety and distress evoked by anorexia in patients and their family.

From the perspective of terror management theory, people are innately striving after self-preservation, trying to avoid reminders of imminent death.^{29,30} This theory could possibly explain the findings that NRPs to which partners attach the meaning “loss of life” are often talked about as neutral facts without existential meaning by patients avoiding direct confrontation with pending death and attempting to manage existential insecurity.

To our knowledge, this study is the first to explore the meaning attached to NRPs in advanced cancer and, as such, to go beyond the description of the experience. Access to the meaning of a lived experience can only be achieved by an interpretative approach requiring a thorough hermeneutic analysis of the data and intensive discussions within the research team.²⁵ In that way, IPA hands researchers tools to explore profoundly and in a philosophical way the meaning people attach to their life experiences. By using IPA and its double hermeneutic approach, it is possible to uncover aspects in the meaning attached to NRPs that were not described in this context before. Nevertheless, insight in the meaning of a lived experience is paramount to uncover the psychosocial and existential consequences of the experience. The degree of psychosocial and existential distress seems to be related to the appraisal and consequently to the meaning attached to the threat associated with cancer.^{31,32}

Pointing to the loss of all health symbols, the meaning that the patients and partners attach to NRPs can be considered

predominantly negative. It is well known that negative meaning-making in the context of cancer can lead to existential distress, a decrease in quality of life, and increased levels of depression and anxiety.³³ Better insights into the meaning attached to cancer-related experiences and particularly to NRPs could assist nurses and other health care professionals in developing novel approaches in offering personal psychosocial support for patients and their family caregivers challenged by NRPs in advanced cancer.

Strengths and Weaknesses of the Study

This study has several strengths. First, the couples were interviewed concurrently, which was indispensable to evoke interactions and to get a clear view on the interdependency in the meaning attached to NRPs between both partners. By interviewing them together, the patients and partners often supplemented each other's stories, and in some cases, the interview evoked disclosure of new concerns. However, whether to conduct joint interviews or to interview both partners separately is an ongoing discussion.³⁴ Some scholars argue that the presence of the partner might favor giving shared rather than individual accounts of the experience and that conventional rather than honest answers could be evoked. On the contrary, others presume that joint interviews add to trustworthiness of the interview data.^{35,36} Interviewing both partners separately can be disconcerting for the partner when he/she should talk about the patient's illness from a less positive perspective. Moreover, separate interviews more often lead to ethical concerns than joint interviews, for example, when both partners give opposite answers and the reviewer cannot mention this because of research confidentiality.³⁴

Another strength results from the interdisciplinary composition of the research team and the emphasis that was put on teamwork. This allowed an extensive investigation of the data from different perspectives. Moreover, the iterative and inductive analysis cycle, typical for IPA, can ensure a deep and thorough investigation of the studied phenomenon.

This study, however, was also subject to some limits: although the participants talked about their experience from the start of the NRPs until the day of the interview, recall bias hampers the emergence of a clear view in the chronology of the meaning-making process.

Another limitation results from the selection of the participants. All participants were Flemish, white, and raised in an environment and time predominantly governed by the Catholic church. Consequently, the results should be interpreted with caution because they are descriptions of the meaning a small group of patients and family caregivers attach to NRPs. The findings are probably not directly expandable to other communities or ethno-religious groups.



Implications of the Study

Psychosocial support is paramount in the care of families confronted with NRPs in advanced cancer and seems to be predominantly offered by nurses specialized in palliative care. This study has investigated the meaning couples attach to these NRPs. The results could help nurses and other health professionals to recognize the concerns and needs of families challenged by NRPs in advanced cancer and to tailor their psychosocial interventions accordingly to increase self-management. The new insights in the meaning attached to NRPs can inspire scholars to further research in the field. For example, because meaning making is probably determined by culture and environment, it would be of interest to repeat the study in different cultural settings. Furthermore, to explore the developments in meaning during the illness trajectory, future research making use of repeated interviews in a longitudinal study would be appropriate.

CONCLUSION

Nutrition-related problems are inherent to advanced cancer and are perceived as destroying health and leading to loss of physical, psychological, and social health symbols.

This study is the first to explore the meaning patients and their family caregivers attach to NRPs in advanced cancer taking into account a broad, comprehensive stance toward NRPs without focusing on cancer cachexia syndrome or the effects of therapy.

This study highlights that the meaning patients and family caregivers attach to NRPs is individual and dynamic and can change over the illness trajectory. Consequently, NRPs should be evaluated, and the meaning should be explored regularly on different occasions during home visits. As such, optimal assistance could be offered to patients and family caregivers to develop the most appropriate self-management skills.

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