



Christina Melin Johansson, RN, Phd-student
Bertil Axelsson, MD, PhD
Ella Danielson, RN, PhD

Living With Incurable Cancer at the End of Life—Patients' Perceptions on Quality of Life

KEY WORDS

Focus group
Palliative care
Qualitative research
Quality of life
Terminally ill

This study describes incurably ill cancer patients' perceptions of the quality of life at the end of life. Purposeful sampling was used to get as comprehensive descriptions as possible about quality of life. Five patients participated in repeated focus groups. Content analysis showed that the patients emphasized what they could perform and enjoy in daily life, not their shortcomings. Five themes were developed: "valuing ordinariness in life," "maintaining a positive life," "alleviated suffering," "significant relations," and "managing life when ill." The themes describe that the patients could participate in daily and social life despite cancer. Relation with family and palliative team deepened during the progress of illness in such that a resonance developed in communication. Other important findings were that patients' memories helped them to maintain a positive life and that the patients used individual strategies to relive pain by emotional and physical distractions. For the patients, managing life as ill meant taking actions with creative thinking in solving problems as a way to cope and achieve quality of life. These positive findings from the focus groups have led to continued research regarding how patients with incurable cancer perceive quality of life.

Illness affects the quality of life (QoL) in many ways, and when we are struck by illness, we begin to reflect on what QoL really means to us.¹ To many healthy people, cancer is the opposite of QoL because it has a negative meaning that triggers thoughts of immense pain, a grim

death, and dependency. It is difficult to understand that having cancer may in fact facilitate new perspectives on life.² Patients with cancer comprise the largest group in Sweden that is currently offered palliative care,³ and the goal for medical and nursing staff is to provide patients and their

From the Sahlgrenska Academy, Institute of Health and Care Sciences, Göteborgs University, Göteborg, Sweden (Phd-student Johansson and Dr Danielson); Department of Health Science, Mid Sweden University, Östersund, Sweden (Phd-student Johansson); and Department of General Surgery, Östersund Hospital, Östersund, Sweden (Dr Axelsson).

Corresponding author: Christina Melin Johansson, RN, Phd-student, Department of Health Science, Mid Sweden University, SE 831 25 Östersund, Sweden (e-mail:titti.melin-johansson@miun.se).

Accepted for publication October 28, 2005.

relatives with the best possible QoL.⁴ To achieve this, a valid description of the content in QoL at the end of life in the palliative context is needed.

■ Background

In 2000, 10 million people in the world became ill with cancer, 60% of which died that same year due to their illness. In Sweden, 22,000 people die every year in different cancer diagnoses, many of whom require qualified palliative care at some time or other during their illness.⁵

The context for this study is palliative homecare, and previous studies describe that patients at the end of life are often offered palliative care, in accordance with their wishes, at home with support from relatives and professional teams.^{6,7} One important goal for nurses involved in palliative care is to assess the manner in which patients respond to illness, regardless of in which environments these patients are cared for.⁸ Nurses in palliative care have a most worthwhile mission to accomplish, and this is to secure QoL for patients at the end of life.⁹ Quality of life is indeed more in focus here than in any other specific sphere of nursing.¹⁰ Previous studies often describe that to live with cancer is problematic^{11,12} and that patients' needs go unmet.^{13,14} The problems described are related to patients' QoL in palliative care, and very few studies describe what patients with cancer experience as positive aspects of life despite their incurable cancer. In a Dutch study, QoL-related problems are described from physical, psychological, social, and spiritual dimensions. Other problems can be patient's varying demands for information, economical problems, and difficulties in handling different care situations.¹⁵

In a review of 400 articles, many studies were described as being designed to illuminate experiences of physical symptoms such as pain and fatigue. Few studies have focused on psychological and spiritual dimensions.¹⁶ However, it has been emphasized in earlier research that patients in palliative care value the meaningful aspects in life more than bodily functions and relief of physical symptoms.¹⁷ The sense of meaning also contributes to the total QoL both for patients and relatives during the last weeks in life. Another important issue in QoL can be the sense of security, which can be dependent on to what extent patients get support and help from professionals and relatives.¹⁸ According to several authors, it is important to define QoL from the individual's perspective^{17,19} because QoL is a subjective feeling or has a subjective nature.²⁰⁻²³ This means that QoL as a concept is overarching and broad and includes many various aspects of human life.²⁰ Nevertheless, QoL is an important concept in healthcare, and sustaining a good QoL is as important as curing or preserving life.²⁴

In clinical practice, 2 of the authors (CMJ and BA) met patients with incurable cancer, receiving homecare, and who, during certain periods, experienced surprisingly good QoL despite their progressive illness. The authors in this study wanted to explore the patients' perceptions of QoL in an

unprejudiced way and to contribute to a better understanding of how we could maintain and even improve QoL at the end of life relevant to these patients suffering from an incurable cancer.

■ Aim

The aim of this study was to describe patients' perceptions of QoL in incurable cancer at the end of life.

■ Method

Participants

Five participants selected from a group of 25 patients with incurable cancer living in the County of Jämtland in central Sweden participated in this focus group study. The patients were all designated to a palliative homecare team. They all spoke and understood Swedish, and most had lived with the illness for a couple of years or more since they first got their diagnosis. Most had also lived with metastasis since several months and lived only for a short time after the last interview. This criterion is important because cancer is defined as incurable from the day metastasis is confirmed (Table 1). The participants were physically active more than 50% of their waken time and were cared for at home, with support from

❁ **Table 1 • Demographic and Clinical Information**

Demographic Information (N = 5)	
<i>Sex</i>	
Women	3
Men	2
<i>Age</i>	
Median	65 y
Range	54–76 y
<i>Civil status</i>	
Married	2
Single	3
<i>Education</i>	
Upper secondary school	4
College	1
Clinical Information (N = 5)	
<i>Cancer site</i>	
Breast cancer	2
Cancer of the bile duct	1
Prostate cancer	1
Cancer of the bladder	1
<i>Time since verified incurable illness</i>	
Median	8 mo
Range	3–40 mo
<i>Survival after the last focus group interview</i>	
Median	4 mo
Range	38 d–10 mo

relatives and a palliative homecare team. To constitute a motivated and purposeful sample, nurses and physicians in the palliative team were asked to sample possible participants. The nurses suggested presumptive patients who fulfilled the above-mentioned criteria to the first author (CMJ). The patients were then contacted by telephone. When the patients were interested in participation, the first author sent a letter of information. Patients were excluded from the study if it was confirmed by the physicians in the palliative team or from medical records that the patient had dementia or memory problems or if it was assessed by the nurses and physicians in the team that the patient was more confined to bed than he/she is physically active.

Procedure

Presumptive patients were informed by letter on the purpose of the study, the focus group procedures, issues relating to confidentiality, and informed consent. They received the informed consent in writing, which was included with the letter of information. A week after the information was sent, the first author and moderator (CMJ) telephoned the patients for confirmation regarding participation. Patients who agreed to participate were informed of the place and time for the focus group meeting. The focus group met on 3 occasions at a county hospital during a 6-week period in the autumn of 2003. Before each focus group meeting, the moderator contacted the 5 participants by telephone. It was important that the patients had the strength to participate and that they did not feel worried about participating in the focus group. Despite suffering from an incurable illness, the patients made arrangements to enable them to participate because they considered the focus group discussions as important. Each audio-taped focus group discussion took approximately 90 minutes. The room in which the focus group discussions took place was quiet and peaceful, with a pleasantly designed interior and space enough to accommodate a smaller focus group quite comfortably. The tape recorder was placed in the middle of a square table for the best sound recording. Chairs were placed around the table to facilitate eye contact between the participants. Coffee or tea, sandwiches, cookies, and fruit were served after the interviews.

The purpose of the first meeting was to investigate the patients' perceptions of how the illness influenced QoL in daily life. It was important to commence the first meeting with the focus group with a broad and open question and in an unprejudiced way to acquire as profuse information as possible. The key question was "Please describe what it is like to live with incurable cancer." The intention with the second focus group meeting was to discuss existential questions. The key question was "Please describe what you consider as meaningful in life." In the third and last focus group meeting, the participants were asked to describe the concept "quality of life" from the key question "When you hear the word quality of life what is the first thing you think of?"

The moderator (CMJ) carried out the focus group meetings, and the assisting moderator (BA) took notes (which

were not used in the analysis) in case the tape recorder broke down. A few rules were introduced at the beginning of the 3 focus group meetings.^{25,26} Before each key question, opening and introductory questions were asked to provide the patients an opportunity to tell the others about themselves. After every key question, transition and ending questions were asked, for example, what the patients thought had been the most important issue during the discussions.²⁵ After each focus group meeting, the moderators discussed what they considered had been most significant findings during the meeting.

Analysis

Qualitative analysis of focus groups can be used to search for trends and patterns in a text, and the method of analysis should be practical, systematic, and verifiable.²⁵ With this in mind, content analysis inspired by Krippendorff²⁷ was selected. Content analysis can be used in several ways, but the important issue is that the text analyzed should take place in a specific context chosen by the researcher. The purpose of the analysis was to describe and interpret the concealed message in the texts. The analysis of data proceeded according to the following steps:

1. The first author (CMJ) listened to the tapes and read the verbatim texts (150 pages) several times; this reading gave an initial understanding of the text. The other authors (BA and ED) also read the text several times.
2. During the reading of the texts, key words for each paragraph were written down in the right margin. They were a help to organizing the text and to finding parts that had similar content.
3. The texts from all 3 focus groups formed 1 text. To better check the parts in the whole text, the text of first focus group discussion was marked with a red color; that of the second, with blue; and that of the third, with black. These colors made it obvious what meaning unit belonged to which focus group.
4. Meaning units that related to QoL were removed from this whole text and were arranged in a database program (Microsoft Word). This text formed a new text with meaning units that was placed for further analysis in a schematic table. In this analysis, condensed meaning units, codes, subthemes, and themes emerged from these meaning units. This is illustrated with 1 example in Table 2.

The analysis was performed by the first author (CMJ). The second (BA) and third (ED) authors examined the analysis. All the authors had several meetings in which they discussed the most trustworthy way of presenting data.

Ethical Considerations

The Ethical Committee (Um No. 01-320011113) at the Medical Faculty, Umeå University, approved the study. In the focus group discussions, people are afforded the opportunity to decide to what extent they will share their opinions and experiences with the group. For example, they can choose not

❁ **Table 2 • Example of Meaning Unit, Condensed Meaning Unit, Code, Subtheme, and Theme**

Meaning Unit	Condensed Meaning Unit	Code	Subtheme	Theme
“I have felt really well today. Pain, well it’s like every other day, but today has been a really good day...And I was fishing at the weekend, which was really positive, and in this weather! Using nets and everything that’s hard work. My shoulder is a problem, hurts all over. Difficult to use a net. But I found it most enjoyable...”	Feel really well when free of pain and are able to carry out their hobbies.	Free of pain. Able to be active.	Physical well-being	Alleviated suffering

to talk about sensitive matters. Despite this, participants may still feel that they reveal too much of themselves in front of the others in the group. To prevent this, it is important for the moderator to create an atmosphere in which the participants feel secure and will experience the situation as meaningful.

■ Findings

Five themes, with relevant subthemes, and their relation to each key question from focus group discussions 1 to 3 are presented in Table 3 and exemplified with relevant quotations in Table 4.

Valuing Ordinarity in Daily Life

The theme “valuing ordinariness in daily life” consists of the subthemes “to appreciate normal things” and “to feel functional.”

“To appreciate normal things” was described as a feeling of satisfaction with life when the patients were able to carry out activities throughout the day. The patients explained that despite the circumstances, they felt satisfied with being able to do housework and happy when they went out for a ride in the car with relatives or friends. They were glad to be able to perform the ordinary tasks of daily life.

“To feel functional” was described as being free from pain and fatigue as possible and being able to balance rest and physical activity. The importance of having the physical strength to do things that they appreciated, like gardening or other spare-time occupations, without being dependent on others was highlighted. It was also essential to feel psychologically stable by keeping in good spirit and not being anxious or unhappy. The patients stated that it was important to live their lives more or less as they did before they became ill.

Alleviated Suffering

The theme “alleviated suffering” consists of the subthemes “physical well-being,” “psychological well-being,” and “personal strategies to relieve pain.”

“Physical well-being” was described as being free from physical symptoms, particularly pain, for example, pain in the back or head. It was also important to be free from shortness of breath, which contributed to increased fatigue, and to maintain a good appetite with the aid of pharmaceutical treatment, like cortisone. Being able to sleep at night, preferably several hours, and having adequate pain relief made it easier to do what one really wanted to do.

“Psychological well-being” was illustrated not only as being free from physical pain but also as being relieved of anxiety and depression, which was considered to be equally important as

❁ **Table 3 • Themes, Subthemes, and Key Questions Related to the Themes**

Themes	Subthemes	Key Questions Related to the Themes
Valuing ordinariness in daily life	To appreciate normal things To feel functional	“Please describe what it is like to live with incurable cancer”
Alleviated suffering	Physical well-being Psychological well-being Personal strategies to relieve pain	
Maintaining a positive life	Keeping memories alive The feeling of being needed	“Please describe what you consider meaningful in life”
Significant relations	Essential networks Resonance in communication	“When you hear the word quality of life, what is the first thing you think of?”
Managing life when ill	To be in charge of the situation To be reflective	

☀ **Table 4 • Example of Meaning Units to the Subthemes and Themes**

Meaning Units	Subthemes	Themes
P1. Then it can just be something you want to do that's enjoyable—this helps you feel better. A mild sunny day makes you feel so happy and alert—so many things can make a good day.	To appreciate normal things	Valuing ordinariness in daily life
P4. I own my house and can often feel that I want to work in the garden, or paint or something and I find satisfaction in being able to do some of those things—you get a good feeling from being able to do things you want to or get on with a hobby.	To feel functional	Valuing ordinariness in daily life
P4. Well, waking up free from pain is really important.	Physical well-being	Alleviated suffering
P1. It sometimes feels hard to keep your spirit up or get on with things—when you're as old as I am anyway. But it's better to try and find some quality in life instead of going around feeling upset and sad and not wanting to do things.	Psychological well-being	Alleviated suffering
P2. I can come home and get on with lots of different housework and the time passes so quickly and I don't think about having a sore back. I really don't.	Personal strategies to relieve pain	Alleviated suffering
P2. Just to sit on a tree stub and listen to the silence, and the birds, and dream. Well, and to pick a lot of berries and so on. It was always fun. And you got a lot of exercise to.	Keeping memories alive	Maintaining a positive life
P1. Then I feel that there are people who care about me and think about me—try to help me feel good and be happy.	The feeling of being needed	Maintaining a positive life
P5. Of course I have a very good friend called B. And then I have my ex sister-in-law whose name is Y. They keep in touch—and my daughter of course.	Essential networks	Significant relations
P1. The most important thing is to have people who care about you—it feels better when someone wonders how you are getting on and how you feel—if you are in a lot of pain or not. This doesn't necessarily mean that you're dying, just that they are trying to share things with you.	Resonance in communication	Significant relations
P3. A lot is up to you yourself—you have to try.	To be in charge of the situation	Managing life when ill
P2. Mm. No, you just make things worse for yourself if you go around thinking "good grief, what a terrible life."	To be reflective	Managing life when ill

gaining physical pain relief. "Psychological well-being" emerged when one patient received pharmaceutical treatment for anxiety and depression because this helped her to stop crying and escape despair. Her will to live increased, and she expressed that it was good to be free from psychological suffering, such as feelings of unhappiness, and that it was positive to be able to experience QoL while still alive.

"Personal strategies to relieve pain" was exemplified not only by taking extra doses of drugs, for example, morphine, when pain broke through but also by the patient's personal strategies, which diverted attention from the pain and helped serve as pain relief. Keeping oneself occupied with different tasks in or outside the home, being important to others, and the sense of making other people happy helped them to ignore pain.

Maintaining a Positive Life

The theme "maintaining a positive life" consists of the subthemes "keeping memories alive" and "the feeling of being needed."

"Keeping memories alive" was described as meaningful because the patients have positive things to remember, dream of, and long for now that they are ill. For example, they described how they enjoyed as healthy being out in nature, hunting or picking berries, or just sitting on a tree stub listening to the birds—activities that they are not able to

perform anymore. Other memories that they described as happy memories were what it was like to travel abroad and experience other cultures and all good memories that reflect the positive life they lived when they were free from incurable illness that may serve as a source of inspiration to maintain a positive life.

"The feeling of being needed" was a positive feeling that the patients described as having been present in most part of their lives. This feeling could be present, for example, when relatives and friends showed that they still counted on them and needed their advice or support about family matters. The patients described this as being seen as the humans they are and not only as an ill person. "The feeling of being needed" by others was also important when the patients were alone and were occupied with, for example, reading or embroidery because it strengthened their self-esteem. This was meaningful because it helped them to keep their interest in what was happening in the world around them and to find motivation to go on living.

Significant Relations

The theme "significant relations" consists of the subthemes "essential networks" and "resonance in communication."

"Essential networks" was the family, friends, professionals, and the religious network. The network of family included

spouses, children, sisters and brothers, old and new friends, fellow workers, and pets. It was essential to have spouses to talk to about the illness and to have daily contact with their children and siblings for emotional support. Support from old and new friends was also important, as was keeping in touch with fellow workers. Pets were essential, and one patient described how the cat came to her every night and rested on her arm. The network of professionals consisted of nurses and physicians. Having professional support from both nursing staff on the wards and the palliative homecare team was very important. For example, the patients described how important it was for their feeling of security that it was easy to get in touch with nurses and physicians in the palliative homecare team and that the nurses made home visits even if patients lived several miles outside the town. The religious network consisted of chaplains from the palliative team and the chaplains from the local parish who met them with understanding and warmth and had the ability to invite the parishioner to Communion. "Essential networks" was mentioned as important for the patients' social life and had a positive meaning because it meant that the patients had access to emotional support from the family and from the professionals.

"Resonance in communication" with family and nursing staff was illuminated as being particularly important. It implied the significance that there was a mutual understanding in the relation. Regarding communication with the family, the patients described the importance of having a spouse to talk with at home. If they were single, they talked to friends and did things they that enjoyed with them, which gave a feeling of alertness. "Resonance in communication" with the family also implied the importance of family members listening to their problems when they did not feel very well. In addition, the patients could listen to the family members and be responsive to their problems.

In the communication with nursing staff, the patients described that when nurses and physicians in the palliative homecare team had positive talks with them, they felt positive themselves. They did not have any negative feelings about the staff because the nurses were considered ordinary people. The nurses were perceived as positive, committed, and having control of the situation. The continuous contact by telephone made it possible for the patients to recognize the nurses' voices, and if they visited the nurses' office, they recognized the different faces. This brought a positive sense of knowing the staff, which in turn gave a sense of security in knowing whom to turn to, ask questions, and get help.

Managing Life When Ill

The theme "managing life when ill" was described with the subthemes "to be in charge of the situation" and "to be reflective."

"To be in charge of the situation" was illustrated by taking charge of difficult situations, being stubborn, and feeling motivated not to give up. This was an important feeling because the patients felt that they had so much more to give in life. Many things depended on how they solved different

situations. For example, the patients described that it was not possible to go on with life if they were worried or stopped making plans. Thus, they planned and prepared themselves and their family on how they wanted things to be when they died. It was illuminated that the patients controlled the illness by adjusting to it by rearranging their lives and by coming to terms with the fact that they could not live their lives as they had done previously. Despite this, the patients stated that being in charge of the situation increased their positive coping strategies and helped them to live as optimal as possible.

"To be reflective" was described by considering what was important in life and reflecting on the present QoL as compared with that when they were healthy individuals. For example, the patients reasoned with themselves that the important thing was to live as fully as possible and make the most of every day. They explained that material things did not matter; what mattered instead was to endeavor to be the person you had always been and to make the best of the present situation. There was no point in thinking of negative thoughts, which only served to make one miserable; it was better to be active and do and think positively to facilitate the situation. They believed that they had hidden forces that helped them cope with the situation and that they sometimes had a better QoL now than when they were healthy. To manage life when ill was important to the patients' QoL because it gave them a sense of being independent and a feeling that they could cope with the situation despite incurable illness. They independently took important decisions about their present lives and the future, and they still had a clear mind to do this.

■ Discussion

This study shows that QoL at the end of life had a positive meaning for patients with incurable cancer. It also shows that patients could enjoy, appreciate, and participate in social events despite incurable cancer. Discussions on QoL can be rather optimistic because of the patients' positive adjustment to life.²⁸ In this study, the patients expressed the positive meaning of QoL more or less throughout the repeated focus group meetings. This could be because the patients in this focus group, in general, emphasized what they actually could complete in daily life and not on their shortcomings.

The positive meaning in having a social life was expressed by the patients more or less throughout the repeated focus group discussions. The finding "valuing ordinariness in daily life" shows that the patients appreciated their lives and lived the way they were used to. This, of course, made it possible for them to participate in a daily social life, and relatives still counted on them. Similar findings concerning a social dimension of QoL was described in another study, in which the social dimension was more important than the physical and psychological dimensions.²⁹ A study among women with chronic illness showed how they struggled to find ordinariness and a place for the illness in their lives.³⁰ Our study shows the opposite; that is, the patients did not have to struggle to live as usual, maybe because of the fact that their

illness no longer distressed them. We also found that to “keep in good spirit” and being positive were important to be able to value ordinariness in daily life. This was also verified by other studies.^{29,31}

Another finding in this study concerning having a social life is “significant relations.” It illustrates the importance of having “essential networks” and that communication is important. “Resonance in communication” is described from the patients’ point of view as the presence of an “echo” in the communication. The resonance manifested itself in an expression of shared understanding between relatives and the homecare team. This is described in another study among nurses as the ability to bond with the patient and have a human-to-human relation.³² Nurses’ communication skills are sometimes described as insufficient because they only chat with the patients. However, this social chatty conversation does have a purpose in cancer care because it provides a positive and cheerful atmosphere.³³ In our study, resonance is further consistent with the relation being formed on the exchange of positive thoughts and feelings between the person who is ill and a family member or between the ill person and the nurse or physician. This is also described earlier in a review as a phenomenon that connects people.³⁴ Having resonance in the communication in our study means something else and is more powerful than the word “interaction.” “Resonance in communication” describes a deeper relation that patients with incurable cancer may develop during a longer period of time in the care they receive from nurses and physicians.

The finding “alleviated suffering” in this study describes the importance of being free from both physical and psychological pain. It had a positive meaning because it enabled patients to do as much as they wanted in daily life. Inadequately treated cancer pain has a negative effect on psychological and physical functions,³⁵ and there is a relationship between pain intensity and psychological status.³⁶ The concept “alleviated suffering” is described in different ways in earlier studies.^{37–39} Our study shows that to alleviate suffering, the patients used individual strategies to relieve and divert pain. These consist of non-pharmacological strategies that can be used to combat less severe pain. Nonpharmacological strategies were described as keeping oneself occupied with different tasks in or outside the home, and being important to and making other people happy helped them disregard minor pain when it breaks through. This kind of strategy for distracting pain has not been very well described regarding patients with incurable cancer. However, the use of individual strategies used by patients with chronic pain has been described in other studies^{28,40,41} but are often neglected by professionals in cancer care.⁴²

“Maintaining a positive life” in this study is a finding from the discussion of what is meaningful in life and describes that having positive memories is important for the patients’ psychological well-being. Memories as a QoL ingredient in palliative care has not been emphasized in literature. Two studies have recently investigated the importance of memories.^{43,44} For example, women being treated for breast cancer experienced memories as negative because they remembered unpleasant effects of the treatment.⁴³ In the other study, it

was shown that memories for critically ill patients in intensive care varied from having no memories to having intensive recalls of certain events.⁴⁴ “Keeping memories alive” made it possible for the patients in our study to relive the pleasant experiences that they had when they were healthy. Good memories that reflect the positive life that the patients lived when they were free from incurable illness may serve as a source of inspiration to maintain a positive life as ill.

In this study, it was difficult for the patients to talk about existential issues as meaning in life. This could be due to the fact that they had not previously, at any time during their life, reflected on meaningfulness, or maybe it was just too complex to talk about when suffering from incurable cancer at the end of life. This reluctance to talk about meaning in life can also be due to the fact that the patients, by not talking about the issue, avoided becoming sad and anxious. This is described in a review as self-protection from or denial of psychological distress in physical illness and can be a way to facilitate coping in difficult situations.⁴⁵ In our study, another reason for not wanting to talk about meaningfulness could depend on the fact that the issue was raised in a focus group. It has been shown that in individual interviews, patients with life-threatening illness are willing to talk about how they find meaning in life despite the illness.⁴⁶

The finding “managing life when ill” in this study illustrated how the patients handled their situation as an ill person. To manage life as ill meant taking actions that involved creative thinking to solve problems as a way to cope and achieve QoL. It is shown in another study that self-management can be used as a strategy to create order in life in contrast to disorder and is something essential in a person’s life and social context.⁴⁷ Patients can optimize their inner resources and insights despite illness, through resilience, to overcome barriers in their lives.⁴⁸ By managing life as ill, the patients can still “be going strong” despite incurable illness at the end of life and actually experience a rather good QoL.

■ Methodological Considerations

The number of participants (only 5) involved in this focus group study was limited, and the study took place in a single healthcare setting. One of the study’s strengths was that the focus group discussions were carried out on 3 occasions. The convenience sampling approach that included patients who were still active for more than 50% of the time they were awake made it possible to involve those who had the motivation and capacity to verbalize their perceptions. Nonparticipants did not have the same opportunity to share their opinions on QoL. This means that if other participants were included in the study, the findings might have been different.

It is difficult for a moderator to predict and be fully prepared for what will happen in focus group discussions. In this focus group, most patients had a positive attitude that could influence the other patients in the group to be more positive than they usually were. It was also rather difficult to foresee if the patients would talk about meaning in life with

some difficulties. In the beginning of the discussion, the patients preferred to talk about what was meaningful in the society rather than what was meaningful to them.

The authors' various experiences could be a weakness if the researchers are not clear on the meaning of preunderstanding and preconceptions. Therefore, we spent considerable time in the research group clarifying the best way to investigate and analyze QoL in patients with incurable cancer. We tried to give prominence to the participants' values and withhold our own in the process of analysis. To make the process discernible, we provided an example of how the analysis was performed; the findings were validated with quotations and with similar findings in other studies.

■ Conclusions

This study shows that QoL at the end of life has a positive meaning for patients with incurable cancer. The findings in this study were identified through 5 themes of relevance relating to QoL, namely, "valuing ordinariness in life," "significant relations," "maintaining a positive life," "alleviated suffering," and "managing life when ill." These themes describe that the patients emphasized what they could perform and enjoy in daily life and not their shortcomings. The patients could participate in and appreciate daily and social life despite their cancer. In line with other studies, this study shows that the patients' relation with their family and the palliative team deepened during the progress of illness, wherein a resonance had developed in communication. One important finding was that patients' memories helped them to maintain a positive life that was not described in earlier palliative care studies. Another important finding was that the patients used individual strategies to relieve pain via emotional and physical distractions. For the patients, managing life as ill meant taking actions with creative thinking in solving problems as a way to cope with and achieve QoL.

On the whole, this present study imparts a small, additional understanding of how patients in this particular context perceive QoL. These positive findings from the focus groups have led to continued research regarding how patients with incurable cancer perceive QoL.

■ Implications

This study indicates that nurses in palliative care should not focus only on problems regarding patients with incurable cancer at the end of life. It is as important for the palliative care staff to focus on positive QoL-related issues and to encourage and help patients verbalize positive aspects in their individual lives. One way is to empower the patients to talk about what they enjoyed in life in the past and what they enjoy in life at the present and inquire on matters in life that can improve QoL. Nurses and other staff can also encourage the patients to participate in a social life as much as they have the strength to

do so before the illness progresses and before the patients become more confined to a bed.

ACKNOWLEDGMENTS

The Swedish Cancer Society and Mid Sweden University, Sweden, funded this study. We also want to thank the participants for the heroic manner in which they contributed to this study.

References

1. Rustoen T. *Livskvalitet—En Utmaning för Sjuksköterskan*. [Quality of Life. A Challenge for Nurses.] Oslo: Almqvist and Wiksell; 1993.
2. Glaus A. Quality of life—a measure of the quality of nursing care? *Support Care*. 1993;1:119–123.
3. Socialstyrelsen. *Sjukvården i Sverige 1998* (Swe) [Health Care in Sweden 1998]. Available at: www.sos.se/fulltext/9800-99/9800-99d.htm. Accessed November 4, 2002.
4. World Health Organization. *National Cancer Control Programmes: Policies and Managerial Guidelines*. 2nd ed. Geneva; 2002. Available at: <http://www.who.int/cancer/media/en/408.pdf>. Accessed March 9, 2005.
5. Socialstyrelsen. *Dödsorsaker 2002* (Swe) [Causes of Death 2002]. Available at: <http://www.socialstyrelsen.se/NR/rdonlyres/05714583-0572-4EDF-9E1C-96E5DC0DA947/2721/2004425reviderad.pdf>. Accessed March 30, 2005.
6. Lamb GS. Conceptual and methodological issues in nurse case management. *Adv Nurs Sci*. 1992;15:16–24.
7. Wennman-Larsen A, Tishelman C. Advanced home care for cancer patients at the end of life: a qualitative study of hopes and expectations of family caregivers. *Scand J Caring Sci*. 2002;16:240–247.
8. King CR, Haberman M, Berry DL, et al. Quality of life and the cancer experience: the state-of-the-knowledge. *Oncol Nurs Forum*. 1997;24:27–41.
9. Matzo ML, Sherman DW. Palliative care nursing: ensuring competent care at the end of life. *Geriatr Nurs*. 2001;22:288–292.
10. Annells M, Koch T. 'The real stuff': implications for nursing assessing and measuring a terminally ill person's quality of life. *J Clin Nurs*. 2001; 10:806–812.
11. Osse BHP, Vernooij-Dassen MJFJ, Shade E, Grol RPTM. The problems experienced by patients with cancer and their needs for palliative care. *Support Care Cancer*. 2005. Available at: http://www.springerlink.com/media/HA03EAP9XM7TYJBDHN2G/Contributions/X/A/B/M/XABM1U2WJ9R20676_html/fulltext.html. Accessed March 4, 2005.
12. Kaya F, Feustel D. Prostate cancer: palliative care and pain relief. *Prostate Cancer Prostatic Dis*. 2004;7:311–315.
13. Soothill K, Morris SM, Harman J, Francis B, Thomas C, McIlmurray MB. The significant unmet needs of cancer patients: probing psychosocial concerns. *Support Care Cancer*. 2001;9:597–605.
14. Sanson-Fisher R, Girgis A, Boyes A, Bonevski B, Burton L, Cook P. The unmet supportive care needs of patients with cancer. *Cancer*. 2000;88: 226–237.
15. Osse BHP, Vernooij-Dassen MJFJ, Schade E, de Vree B, van den Muijsenbergh METC, Grol RPTM. Problems to discuss with cancer patients in palliative care: a comprehensive approach. *Patient Educ Couns*. 2002;47:195–204.
16. George LK. Research design in end-of-life research: state of science. *Gerontologist*. 2002;42:86–98.
17. Stewart AL, Teno J, Patrick DL, Lynn J. The concept of quality of life of dying persons in the context of health care. *J Pain Symp Manage*. 1999;17:93–108.
18. Axelsson B, Sjöden PO. Quality of life of cancer patients and their spouses in palliative home care. *Palliat Med*. 1998;12:29–39.
19. Calman KC. Quality of life in cancer patients—an hypothesis. *J Med Ethics*. 1984;10:124–127.
20. Kaasa S, Loge JH. Quality of life in palliative care: principles and practice. *Palliat Med*. 2003;17:11–20.

21. Cooley M. Quality of life in persons with non-small cell lung cancer: a concept analysis. *Cancer Nurs.* 1998;21:151-161.
22. Haas BK. A multidisciplinary concept analysis of quality of life. *West J Nurs Res.* 1999;21:728-742.
23. Zhan L. Quality of life: conceptual and measurement issues. *J Adv Nurs.* 1992;17:795-800.
24. Meeberg GA. Quality of life: a concept analysis. *J Adv Nurs.* 1993;18:32-38.
25. Krueger RA, Casey MA. *Focus Groups. A Practical Guide for Applied Research.* 3rd ed. Thousands Oaks: Sage; 2000.
26. Hudson P. Focus group interviews: a guide for palliative care researcher and clinicians. *Int J Palliat Nurs.* 2003;9:202-207.
27. Krippendorff K. *Content Analysis. An Introduction to its Methodology,* 2nd ed. London: Sage; 2004.
28. Blomqvist K, Edberg AK. Living with persistent pain: experiences of older people receiving home care. *J Adv Nurs.* 2002;40:297-306.
29. Larsson G, Haglund K, Von Essen L. Distress, quality of life and strategies to "keep a good mood" in patients with carcinoid tumours: patient and staff perceptions. *Eur J Cancer Care.* 2002;12:46-57.
30. Kralik D. The quest for ordinariness: transition experienced by midlife women living with chronic illness. *J Adv Nurs.* 2002;39:146-154.
31. O'Baugh J, Wilkes LM, Luke S, George A. 'Being positive': perceptions of patients with cancer and their nurses. *J Adv Nurs.* 2003;44:262-270.
32. Hartrick G. Relational capacity: the foundation for interpersonal nursing practice. *J Adv Nurs.* 1997;26:523-528.
33. Jarrett NJ, Payne SA. Creating and maintaining 'optimism' in cancer care communication. *Int J Nurs Stud.* 2000;37:81-90.
34. Fredriksson L. Modes on relating in caring conversation: a research synthesis on presence, touch and listening. *J Adv Nurs.* 1999;5:1167-1176.
35. Strang P. Cancer pain—a provoker of emotional, social and existential distress. *Acta Oncol.* 1998;37:641-644.
36. Zimmerman L, Story KT, Gaston-Johansson F, Rowles JR. Psychological variables and cancer pain. *Cancer Nurs.* 1996;19:44-53.
37. Tierney RM, Horton SM, Hannan TJ, Tierney WM. Relationship between symptom relief, quality of life, and satisfaction with hospice care. *Palliat Med.* 1998;12:333-344.
38. Rehnsfeldt A, Eriksson K. The progression of suffering implies alleviated suffering. *Scand J Caring Sci.* 2004;18:264-272.
39. Öhlen J, Bengtsson J, Skott C, Segesten K. Being in a lived retreat—embodied meaning of alleviated suffering. *Cancer Nurs.* 2002;25:318-325.
40. Jakobsson U, Hallberg IR, Westergren A. Pain management in elderly persons who require assistance with activities of daily living: a comparison of those living at home with those in special accommodations. *Eur J Pain.* 2004;8:335-344.
41. Lansbury G. Chronic pain management: qualitative study of elderly people's preferred coping strategies and barriers to management. *Disabil Rehabil.* 2000;22:2-14.
42. Rhiner M, Ferrell BR, Ferrell BA, Grant MM. A structured intervention program for cancer pain. *Cancer Pract.* 1993;1:137-143.
43. Thomas-MacLean R. Memories of treatment: the immediacy of breast cancer. *Qual Health Res.* 2004;14:628-643.
44. Adamson H, Murgu M, Boyle M, Kerr S, Crawford M, Elliott D. Memories of intensive care and experiences of survivors of a critical illness: an interview study. *Intensive Crit Care Nurs.* 2004;20:257-263.
45. Goldbeck R. Denial in physical illness. *J Psychosom Res.* 1997;6:575-593.
46. Albaugh JA. Spirituality and life-threatening illness: a phenomenologic study. *Oncol Nurs Forum.* 2003;45:93-4598.
47. Kralik D, Koch T, Price K, Howard N. Chronic illness self-management: taking action to create order. *J Clin Nurs.* 2004;13:259-267.
48. Nakashima M, Canda ER. Positive dying and resiliency in later life: a qualitative study. *J Aging Stud.* 2005;19:109-125.



Conference Calendar

Educational opportunities relevant to cancer are presented in this feature. Nurses and other health professionals are invited to submit notices of symposia, workshops, and continuing education offerings to: Carol Reed Ash, Editor, *Cancer Nursing*, University of Florida, College of Nursing, P.O. Box 100187, Gainesville, FL 32611. Academic programs leading to advanced degrees in cancer nursing will be listed at the request of the sponsoring agency or institution. Selections of items for review will be based on their relevance to cancer care and the availability of space. Items must be submitted at least four months prior to the program date.

Lymphoma & Myeloma 2006, October 19-21, 2006. New York, NY. www.imedex.com. Contact: s.clemmons@imedex.com.

13th Hong Kong International Cancer Congress & 3rd Annual Meeting of Centre for Cancer Research, November 15-17, 2006. The University of Hong Kong, www.hkicc.org. Contact: Congress Secretariat: hkicc06@hku.hk.

Florida Association of Pediatric Tumor Programs, Inc. (FAPTP) 29th Annual Seminar: Advances in Pediatric Hematology/Oncology, November 16-18, 2006. TradeWinds Island Grand Resort, St. Petersburg Beach, Florida. <http://www.faptp.org>.

11th Annual Perspectives in Thoracic Oncology, November 17-18, 2006. New York, NY. www.imedex.com. Contact: s.clemmons@imedex.com.

5th World Conference on Breast Cancer, June 4-8, 2008. Winnipeg, Manitoba, Canada. mail@wcbcf.ca.