Quality of life in oncology: Nurses’ perceptions, values and behaviours

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Abstract

Quality of life is an important dimension of cancer care. Yet, within our current environment of fiscal restraint, restructuring and cancer care system reform, pressures exist which may make it difficult to provide care which attends to issues of quality of life. Oncology nurses are key providers of cancer care and their perspectives on quality of life for cancer patients are very important. In addition, much of the satisfaction oncology nurses experience in their practice emerges from matters related to attending to quality of life issues. Are oncology nurses currently able to incorporate quality of life issues into their daily care of patients? How are they doing so?

The purpose of this qualitative study is to identify major themes and dimensions of nurses’ perceptions and values related to quality of life and create a profile of the oncology nurse’s role in integrating quality of life in nursing practice. A total of 25 oncology nurses in regional cancer centres across Ontario were interviewed. Each semi-structured interview was tape-recorded and transcribed. Analysis was completed to identify the major themes and dimensions. This presentation will report the findings from the study and will focus on understanding the existing values oncology nurses hold surrounding quality of life, how quality of life is conceptualized, and the patterns of practice and decision-making regarding quality of life.

I am delighted to have been asked to present the Schering Lecture to you this year. It is truly an honour to have been selected from among worthy colleagues to share the results of this study with you.

The focus of the lecture is on oncology nurses and their perspectives about quality of life. It is based on research concerning oncology nurses’ perceptions, values and behaviours regarding quality of life for their patients.

Quality of life in oncology should be a concern for a variety of reasons. In oncology, we use a number of therapeutic options that have both short-term and long-term effects for patients. We work with oncologists who have been trained and are rewarded for extending patient survival, accounting for the focus of their clinical and research activity (Beziak et al, 1997). We have seen limited gains in cure of cancer and observe the chronic nature of many cancers. Limited resources exist in the health system and there are ever-rising costs for care. I am sure everyone here has been touched by restructuring and downsizing as agencies try to cope with those rising costs. Finally, there has been considerable work done to design tools for use in clinical trials to measure quality of life (Strain, 1991). These tools are used more frequently as endpoints in trials (Till et al, 1994); yet many questions can be raised regarding what they actually measure.

I believe quality of life is a central aspect of nursing practice. When this research was started I wanted to determine if quality of life was central in the real world of oncology nursing. As we drew toward the close of the 1990s, I wanted to know how oncology nurses were handling the issues of quality of life for their patients. If we could understand the existing values, conceptualizations and patterns of practice regarding quality of life, and understand how nurses are making decisions about quality of life, then we would be in a position to understand if gaps in practice exist and be able to design appropriate modifications.

Purpose and methods

The purpose of this work was to identify major themes and components of nurses’ perceptions and values related to quality of life. Additionally, I was interested in creating a profile of the oncology nurse’s role in integrating quality of life in nursing practice.

The participants were 25 nursing staff from regional cancer centres across Ontario. All volunteered to be interviewed. The average number of years they had been in nursing was 22.7 (range 10-33) and in oncology nursing was 10.7 (range two to 27). This was a very experienced group of nurses. Additionally, the participants were from a cross-section of oncology specialties: radiation oncology (7), medical oncology (5), chemotherapy (5), blended radiation/medical/chemotherapy (3), palliative care (3), community nursing (1) and clinical trials (1).

The analysis in this study consisted of identifying major themes from across the transcribed interviews. For the purposes of this presentation, I will focus on six topic areas from the analysis.

Most of the presentation is recounted in the words of your colleagues in oncology nursing. The words have been woven to create a story which I hope will have meaning for you. I hope this presentation will trigger memories for you about your practice, will...
stimulate you to think about your practice, and will make visible or illuminate this aspect of oncology nursing practice. I hope you will hear familiar ideas and will see that we share many common experiences as oncology nurses. Actually, I would be very interested to hear if the data I share with you today actually reflects your practice experience.

There are six topic areas I would like to talk about this morning. They include: defining quality of life, personal awareness of quality of life, assessing quality of life, nurses’ role in quality of life, conflicts and resolutions, and what helps and what hinders nurses attending to quality of life issues. I plan to highlight each area by sharing the data provided by the nurse participants. As with other studies of this type, when nurses are the participants in the study, I am struck by the wisdom evident in the interviews. I hope that wisdom will be evident as I share their words with you.

**Defining quality of life**

The participants were asked how they defined quality of life for themselves and how they defined it for their cancer patients. The importance and value of quality of life to the participants were clear in all the interviews. Many participants saw quality of life as having multiple dimensions and the importance assigned to each dimension as varying from person to person.

**For self**

For themselves, participants defined quality of life as being able to do, being able to enjoy and being satisfied.

*I think being able to do what you want to do and having the ability to do it and the health to do it.* (L)

*For me, quality of life, I guess, is living your life feeling content and happy and generally in good health.* (M)

*I think it's a very individual thing to the particular individual. How I see quality of life is the ability of the individual to be able to lead a life that is satisfying to them...being able to function in a daily living situation with a degree of fulfilment. Whatever it is, whether it's mental, spiritual or physical. All these things come together to define that individual as an individual with a quality of life.* (C)

*For me, quality of life makes me think about everyday living. My quality of life is what I do daily...quality of life is dependent upon how you feel each day; what you do each day; how you view each day; and how you think about your day and the future of your life with regards to how you're feeling at the time; and how your health is; how your family life is; what you do as far as working, personal relationships. Family life is really important to me.* (D)

The notion of choosing quality of life over quantity of life for oneself emerged during the interviews.

*I guess it's being allowed or being able to do the things that you like to do in a way that you are comfortable. That you're comfortable physically as well as clear mentally...personally for me, I would rather have a good quality of life and have it shorter than to have a poor quality of life and [live] longer.* (E)

*Life needs to be worth living. Nobody wants to be here for a long time suffering and having no fun. Like there has to be a good reason to live. Life has to be enjoyable. You have to feel you're serving a purpose. If life is just suffering, with no happiness, that to me is not quality.* (M)

Participants described their expectations that quality of life would change over time.

*For myself, I think, it is an individual perspective. And I guess it changes as I go through life as well. My focus will change as things happen in my life. But right now my quality of life is based on the fact that I am healthy, I have security of family and friends, a support network. I have a job and, you know, I have sort of a healthy life outside work as well...they are values and, you know, that becomes an individual thing.* (Y)

Another dimension to quality of life was the notion of being in control and having choices.

*Allowing a person to make the choices that he would like to make, regardless of whether or not you think it's reasonable, and being able to follow through with it and having the choice of control.* (H)

**For patients**

When the participants talked about quality of life for oncology patients, they emphasized many of the same dimensions which they had emphasized for themselves. Quality of life was seen as having many components and being influenced by many factors. Notions about being able to function and good symptom management were frequently cited.

*For patients, I suppose, the things I was talking about for myself would apply. I mean they are values and that becomes an individual thing. And I suppose people with cancer say the same things. People look at quality of life when they're living with cancer as having a good support network and having a loving family, having the support of the health care team, being able to work, being able to conduct their life and not having the cancer interfere too much in what they have always known as a good life.* (Y)

*I think being optimally functional for as long as possible would be a quality of life. The quality of life would be having minimal interference in one's activities of life with disease or treatment.* (I)

*I guess relative to how a person is functioning in accordance with their norms. And whether their current situation has decreased their normal lifestyle as they see it before their illness and the effect of their treatment, whatever it might be, on how their normal lifestyle is affected.* (K)

Well, with patients, that we have a good control of their symptoms. Like good physical, as good physical condition as they can be in. So obviously, pain, nausea, vomiting...good, good control of their symptoms. And if you can't do that then everything else is a strain because that's their primary concern...but almost equal to that is having a good support system and living where they want to be living...being in the physical setting that they want to be in where they feel most comfortable.* (J)

Participants talked about quality of life for cancer patients as being an important consideration in treatment decisions. The dimensions of quality of life vary or shift over time. The definition of each dimension remains the same but the relative importance of the dimensions change. These changes need to be taken into account when making treatment decisions.

*For quality of life I am thinking along the lines of not being ill. When you get up in the morning, what does your day look like? What are you going to face? For some of our chemo patients, are they vomiting? And, too, if that's the way they wake up in the morning, that's pretty miserable. I also think of some of the practical things such as women with young children. Can they get up and have enough energy to be making the meals for their family? Can they do their own laundry? I think it's really demoralizing to have to have someone come in and do all the tasks...the majority of my patients want to be*
Every patient is different. I think it’s what they describe to you. There are some patients, they describe to you, maybe what their home life is or their work life or maybe a combination, or their play life. Sometimes, quality of life...is treating them quickly...when they call in. I think that it’s such an individual thing...For some patients they talk about their physical well-being. For others, it’s their emotional or their relationships or their self-actualization or whatever. (R)

It was evident from the participants’ comments they think the components of quality of life do not change. The same components constitute quality of life. However, priorities or what is considered important shifts. The balance or weighing of the importance of various components changes over time and situations.

I think there are shifts. I think initially people are very frightened and they want to be cured. And whatever that takes, they are willing to put up with a lot if there’s a chance they’re going to be cured. And I almost think they ignore some quality of life issues at that point because the only thing that they can really focus on is being cured of the disease. And when they are not cured of the disease I find that there is definitely a shift. And I think that quality of life issues become far more important at that time. They want to make sure they are going home and there’s going to be some support for them...they want to make sure that, you know, they can come to terms with what’s going on. (R)

If I was talking to a patient, I don’t like to make decisions for them. But I think it’s very, very important to let them know that if they prefer to have two months of better quality time, as opposed to six months of, you know, treatment that was going to make them ill and ultimately was not going to change the course of their disease, that it would be fine to choose. (P)

I think that quality of life for people should be good and that their treatment decisions should be based on providing patients, at any stage of their illness, a good quality or as good as can be provided at whatever stage they’re at. Even in terminal stages you can have good quality of life. (Q)

**Own personal experiences**

Participants described their own personal experiences as influencing their awareness of quality of life. Their own life and work experiences, as well as growing older, contributed to their ideas about quality of life.

I don’t think there is a bigger area of medicine than oncology where you’re going to find the staff that you’re working with had a personal background...And it’s good in a way because it makes you more aware, makes you more in tune with what’s going on with patient and family...and you can understand their feelings, their stress, their discomfort, because you can identify with what they’re dealing with. (O)

For some participants, their experiences with their own family members contributed to their awareness of quality of life issues.

My mother passed away from cancer and that really changed my outlook on quality of life, knowing what she had gone through. And that changed my perspective, being through that personally. (B)

I think we often draw from our life experiences. And personally, my sister died from breast cancer when she was 27. So quality of life was a real issue. And I think when you go through something like that you actually look at things differently, you know. It’s a terrible thing. You certainly don’t wish an experience like that on anyone, but I think it does make you very, very aware of the issues that are important. (P)

Others spoke about patients for whom they had cared and the influence those individuals had had on their awareness of quality of life issues.

Very early on [in my career], I remember a young man. He was 30 something and had leukemia. I thought, “that could be me...” I remember him. He was young and he was gone quickly. I was just traumatized. Probably being exposed to it, one of the first times being exposed to someone with young children. You know, some things really stick in your mind. And that was one of them. And I still, not every day, you know, the odd time, I remember. That was really awful. And that could be anyone. But you make the best of the day that you have, because that’s all you have. (A)

I would say I recognized [quality of life] as a student nurse, possibly with the first death I ever saw because I had no knowledge of death before that. And I remember it was a 40-year-old asthmatic. And when I was in training (which was 30 years ago), 40 was a little beyond middle age - like 60 is now. So I couldn’t understand how a 40-year-old could die all of a sudden. And I think at that point was when I realized all the factors around her life, how important it was. And you learn from each patient. (R)

For others, their work in oncology and being able to build relationships with cancer patients influenced their awareness of quality of life.

...I think I probably never gave a thought to quality of life at all until I got into oncology...Coming to work here and getting involved in clinic, where the life expectancy of patients was generally limited. And I was just beginning to learn what treatments could and could not do for patients...I thought, this is sometimes pretty drastic treatment. Chemotherapy in particular was pretty hard on people. And was this really a good idea given their long-term prognosis was pretty poor? (I)

For me, I started being more aware of quality of life once I started caring for patients on an out-patient basis. I could get to know them as people...just seeing those people over this length of time just sort of shows me how important it is...if you don’t know the patient, you can’t just assume...so I think only when I really started to work at the cancer centre and started working and having a relationship with patients and their families that I really started to think of quality of life issues...and the reward comes from the sitting and listening and hearing what patients have to say. (S)

Others thought that simply getting older, having their own life experiences, influenced their awareness and perceptions about quality of life.

It’s probably grown as I’ve practised, become older and I’ve matured in my own life...the experiences of having my own children, having had three surgeries myself, having a child with an illness, that it’s meant more to me...It’s a developing thing...And I think I am a better nurse now than I was when I was 18. I had more energy, maybe, back then. But over the course of 20 years, you know, I think I can relate to people a lot better now. (N)

**Changes in health care and practice over the years**

Participants spoke of the changes in health care and practice which they observed over the years. The changes have resulted in more attention being paid to quality of life issues.

Some participants observed changes in nursing practice.

When I first started doing oncology nursing it was “your job and don’t get too close to the patients”. Now it certainly has changed as
You have to be realistic about what you can do for people. I think assessment is probably the most important thing that we do. And hopefully you refer back to it and that you remember it when you are dealing with people. (U)

I think it should be a number one question in our situations that we’re dealing with every day with our patients. How is what we are planning on doing going to affect the patient’s quality of life? And sometimes if we answer that, then, the question of what we should do becomes quite clear...I fervently believe that people shouldn’t suffer. So I mean, nonsuffering is quality of life...and the only way to prevent that is to make that an important part of the treatment. (O)

We try to make an assessment of the quality of life. I think it is an underlying part of the overall picture. Although we might not even be consciously thinking that this is what I’m assessing, that is indeed what you’re assessing. And there are perhaps some assumptions that we might make about their quality of life which might not be true. The more I work in outpatients and the more I talk with patients, the more I realize that what we see here and what we assess here isn’t necessarily the real picture either. People put on their best ‘bib and tuck’ for us and certainly put their best face on things. And when we don’t have the opportunity to develop the relationship to the place where you get past that...patients may not be entirely straight with us. And perhaps it’s part of human nature. I think that sometimes the things we are making our decisions on are not necessarily all that valid. (I)

Well, there is no set way of assessing. I think a lot has to do with good assessment skills and being able to relate to the patient and ask the appropriate questions. But, it is a two-way street and it also depends on how much the family or the individual wants to relate to you as well. (B)

Participants described the approaches they use to assess quality of life, emphasizing the importance of a broad perspective and concerns with using a standardized questionnaire.

You really have to listen, You have to be open. The questions shouldn’t be as specific as ‘Do you have pain?’ or ‘Do you have an appetite?’ I think that they really need to be broader, more general. Like, what is important to them right now? What do you see happening in the next while? What sort of hopes and dreams do you have from this moment on? What sorts of things can I do to assist you? Really, in a sense, try to be present and let them direct what is important to them. Quite often it’s quite a surprise, quite different from what you might think. (V)

I think it is really important to have our care driven by the patient. And that’s a bit difficult because that is new. I mean, we’ve always had policies and procedures and standards and standard groups of questions. So we just go with a little list in front of the patient and check everything off and feel quite satisfied that we know everything we need to know about the patient because we’ve gone through our list. But in fact we probably don’t know them very well at all. (Y)

I wonder if we are doing the right thing by having essentially a checklist of things that sort of suggest that if you’re free of all these kinds of symptoms or if you’re living relatively comfortably with all these symptoms, then that supposes that you have good quality of life, you know. I think really it’s only the individual that can tell you, tell me, what quality of life is for them, and it may be quite different. (Y)

On the other hand, some participants wanted a standardized form they could use in their assessment of quality of life.

I guess for me I wish there was maybe a kind of a form. I do these things out of my head, but I don’t know really where I’m going with it...having a definite way of following on a regular basis their quality

Other participants observed changes in the health care system.

We’ve taken giant steps forward. I know that when I first started...working in oncology and treating patients with chemotherapy, quality of life was not addressed...even in institutions, people had to come and sit lined up in halls. People weren’t as open in discussing cancer and so these people just sat there horrified - publicly in a hallway. It was awful. We didn’t have good control of their nausea. We didn’t have good patient scheduling...we were doing the best we could, but when I think back on it, it was horrible...now we can provide our patients with privacy if they need it and someone to listen to them. Oh, we’ve come a long way...we have a focus on treating cancer patients and making their lives better. I think in nursing there’s been a shift...a visible shift totally in that patients’ lives are important. They aren’t numbers. All of a sudden, you know, we’re interested in what can make their life better...we look at the person as a whole. It’s not just like an arm coming in to see an orthopedic surgeon, you know. People have faces and names and that has changed. (M)

Many participants had ideas about why these changes in nursing practice and the health care system had occurred. Their ideas focused on the multidisciplinary team and the growth in awareness of patients’ rights.

Quality of life is starting to get more and more attention paid. It makes me think about the reasons why it’s happening...Is it really because issues of quality of life have been neglected? Or is it because, in the communication around treatment and the whole issue of treatment decisions, there’s a move away from one-sided physician driven decision-making and towards other people having input? Most specifically, obviously, the patient having input in what’s going on. (I)

I think there are more and more people who are better educated about their disease and their illness and they want to know right from the start. They ask pertinent questions and that helps them deal with it...I think we are seeing more and more people who are realizing what a patient’s rights are and so they are requiring of the nurse, their physician, their family, that the questions be answered and their concerns be addressed. So I think people aren’t so afraid to speak up...Patients no longer say, “yes, doctor”. They say “why?”. Over the years there has been a big change. (O)

Other participants felt the change had been within themselves. Their learning and experiences over the years had influenced their practice.

When I was new in oncology I was probably much more sure that I knew what was right or good or beneficial for the individual than I am now. I’m a lot more ready to say, “the reins are in your hands and I know this about the situation.” Or, “I have seen this happen in the past and I know people that have found this beneficial, but the reins are in your hands.” (I)

Assessment of quality of life

Several issues emerged when the participants described their approaches to assessing quality of life. Clearly assessment of quality of life was seen as important, but it presented challenges.
Participants’ approaches in assessing quality of life ranged from informal to formal approaches.

...conversation with your patient. You just know if people are enjoying life or not. I don’t have any difficulty...I always find it’s fairly easy to pick up people who are unhappy and don’t feel life is worthwhile. (M)

Well, I guess it’s half formal and half informal. It’s formal based on what questions are on the history form and then you review it or pick up your questions from there, or your feelings from there. They’re the leads and then you work with it...I don’t ever see anybody and think about what their quality of life is, not consciously, you know...because quality of life is dependent on all those things...I don’t think it is an independent issue...I find it difficult to go back to their quality of life and isolate it. I can’t isolate it. (A)

Participants voiced concerns about using measurement tools to assess quality of life. Quality of life is seen as complex and a function of people’s perception. As a result, the participants perceived quality of life as difficult to measure.

I think it’s a very complex issue. And I think that it’s one that’s hard to measure because I think quality of life for one individual may not be quality of life for another. And so I think it’s a very, very - it’s hard to measure quality of life in someone. (P)

You know, when you give a patient a quality of life thing to fill out and you say to them, “what is your quality of life?” a lot of them really don’t know what that means. And you’ll see a patient who is terminally ill being treated say their quality of life is excellent. And then someone else who’s just been diagnosed or is part-way through treatment and is sailing through things say their quality of life is terrible. So it’s certainly perception, you know. (O)

I usually go over the quality of life, the answers the patient has given, because sometimes what the patient has put down in a written statement is not what they have been telling me. What they’ll say about a time may be different if they’re filling it out a week later if they’re filling it out a month later...Time, as in a lot of other situations, helps to smooth out things and a patient will give completely different answers about the same time frame a month later. (O)

Some participants had observed that more clinical trials studies than had been the case in the past required the patient to complete a quality of life questionnaire. They had concerns about the validity of the assessment and the burden placed upon patients in completing the questionnaires.

...the other thing that we are seeing more and more of than ever before, is that all trials that outpatients are on currently, there’s a quality of life component attached to them, which didn’t happen four years ago...We don’t want our patients to have to fill out too many questionnaires. That’s going to be a conflict...It is also demanding for the patient. And it might be too demanding. (P)

Nurses’ contributions are different

Participants in this study were clear that nurses’ perspectives are different. Nurses bring something different to the care team and to the process of planning for patient care.

Nurses bring different things to a conversation, I never had any question in my mind about that...I think nurses bring practicality into the picture. They are the ones who are saying, “what are your responsibilities at home? Are you still looking after your children, making the meals, doing the laundry and so on? Are you able to reduce what’s being demanded of you in order to cope with what’s being demanded in here?” Nurses are looking more at what I think of as the whole person rather than just the illness...it’s the nurse’s job to bring that perspective into the medical system. This is a medically driven system. Nobody brings that. (I)

Well I think sometimes patients talk more openly to the nurse than they do to the physicians...I think we have a really important role to play in being able to try and talk to them about what options are available to them as far as their treatments and where they want to go as far as their illness or whatever is concerned. I think we play an important role in that. (T)

Nurses would bring the more personal, the home stuff not the systemic stuff...I spend the time with the personal. I mean, most of the time I have read the path report. I know the bottom line. You know where you stand and what’s going to happen. And you try to get a feel for the personal and integrate it. I think there’s two sides. But they go together and they all fit together. And each person has a contribution to make. (A)

And, I don’t know if we might not bring a more compassionate aspect to it. Perhaps we bring the “what if’s” that the patient hasn’t said, that we think might not have been asked. It’s always with the patient in mind that you go back and hash these things out. I think it stops and makes everybody think about the compassionate side of things, about the quality of a cancer patient’s life. (M)

Yes, nurses bring a different perspective...doctors are sort of more realistic. We’re realistic but I think we tend to want to give the patient a little bit more hope. So we tend to look at the other aspects other than just the straight treatment. Like you sort of look at, well, I guess the social issues, the family, the other things in that patient’s life besides their cancer...we sit down and talk...we look more at the whole patient. (S)

Nurses’ role in quality of life

Participants envisioned a range of roles for nurses regarding quality of life. The quotes below illustrate this range in nursing roles including advocate, co-ordinator, educator, facilitator and supporter.

There’s plenty of opportunity for nurses to bring a different perspective for sure. I think that...our focus can be somewhat narrow sometimes when we follow the medical model perspective, because you are very focused on problems and deficits and all those kinds of negative things. You know, where if you have a pain you give a pill...I mean, there are other kinds of things, you know, around relaxation and nutrition...non-traditional sorts of things that can be brought into it. (Y)

I feel very strongly about how we are with patients and this thing, “that’s all we can do for them”. I think we are discovering all the time there’s so much more that we can be doing on our own apart from working with the physician. There is a role for the physician. There is a role for the physician and nurse team. But there’s quite a separate role for the nurse and the patient. (Y)

I think we have a really important role to play in being able to try and talk to them about what options are available to them as far as their treatments and where they want to go, what they would like to do as far as their illness treatment...I think we play an important role in that. (T)

...Sometimes it’s not the cancer, it’s everything else. And I think that’s where the nurse steps in, you know. The cancer’s dealt with by the medical people and the rest of the body and the mind is dealt with by us, you know. (S)
...our job is to inform them of what’s available, not make choices for them. My job is just to make sure they know and be able to pick from that. But whatever that is, we can’t be biased - support him right through. (A)

I certainly think we as nurses can certainly try and teach that there are different options open to them as far as quality of life and there are different ways of doing it. (T)

If a patient said they did not want treatment anymore, I guess I would want to try to get a little more information about why they don’t want it. If anything happened...I guess I would want to know the reason and take it from there...As long as he is well informed...Knew the options and knew what he was walking away from. (M)

It’s up to us to be able to implement other resources so that patients can reach their goals. I see nursing in a pivotal role as co-ordinator, too, in terms of trying to identify what those needs would be and putting those into place through community support and families so that the outcome is what the patient wishes. And I think that when patients feel they’ve lost a sense of control that they’ve lost their battle and their hope of carrying on...[they are] less interested in carrying on in life because their life doesn’t have meaning to them. And what my meaning for them would be is really not what’s important to them. And I think as nurses, we have to respect that and facilitate it. (X)

So if I can help the patient have good pain control, okay. Then they feel better about themselves and do a lot of the things they wanted to do; that they wanted to do but didn’t really have the energy to do, whether it was because of the pain that was dragging them down or whatever. So helping the patient feel good physically and mentally...even knowing that they don’t have a long time, that their length of time is limited...they have to feel good physically whatever the symptoms. (F)

I think it’s a combination of listening and good communication skills. You know, listening to the patient and then helping the patient to communicate their feelings with the physician and with the family. (O)

I think the biggest challenge is to get agreement between the family members...If the family thinks things should be done one way and the patient wants things done another way and the physician is saying, “well, we’ll do...”, then you don’t get the support of the patient because you haven’t solved the conflict first. I think nurses often are mediators in that situation...they play a role in repeating what was said...reiterating what the doctor has explained to make sure their understanding is as it should be...and help the family talk together...or making a referral to psychosocial services. (O)

Conflicts surrounding quality of life

Participants shared the observation that working with quality of life means working at times with conflict. Conflicts surrounding quality of life issues arise between patients and health care professionals, between nurses and physicians and between family members and health care professionals. The conflict arises when different parties hold different goals for a situation.

Well, we can’t fix a lot of things, you know, and I think that becomes a real source of frustration and sometimes conflict between the health care givers and the patient because there comes a time when we can’t answer everything and we can’t fix everything. So then what are we doing? I really believe that, you know, at times like that you really have to depart from the things that we feel are important and address the hopes and dreams of the patient. (V)

I think right from early on that patients don’t want to be told what’s good for them and what isn’t good for them. It’s their life. They know that and this sort of attitude, that “we know what’s good for you or would be better”, it doesn’t work. It just becomes a source of conflict between me and the patient. And having worked in oncology for 25 years, over time you realize that some of this tugging, this pulling that happens between patient and health care professionals is because we keep trying to ram things down their throats. “This is what’s good for you. If you would only do what I tell you, you would be fine.” And patients keep saying “Well you’re not hearing me. I’m not interested in that. There’s another focus that is important to my life right now”. (Y)

I think nurses are particularly sensitive to the issues of quality and sometimes they conflict with physicians on the subject of whether what the physician is suggesting in terms of treatment would impair the quality of life; whether the balance was being properly struck; whether the patient is being totally ignored about everything and that’s a communication thing...I know here there are differences of opinion between nurses and physicians about treatment and they do evolve around quality of life issues. (I)

...and I still think we are battling old line physicians that just don’t have any use for support. I always think they should be put in a hospital bed for 24 hours...The majority here have come along very well. But there are still a few that, well, it’s very difficult, very difficult to get the proper supports for patients sometimes. (P)

Well I think the biggest one you see is not even so much between the physician and the patient, but between the physician and the patient’s family. A patient’s family that’s clinging to time and a patient that’s clinging to quality or comfort. And I guess I’ve seen a few instances where the family cannot let go and the patient desperately wants that. The physician’s caught in the middle. “Can’t you give her...? Can you treat her some more?” That desperation that the family has to continue treatment, to lengthen that time they have until the end because they haven’t dealt with their own need. But the patient’s ready to let go and I think sometimes maybe we listen to the family and not enough to the patient. (O)

I suppose I always feel there is a conflict, but maybe the conflict is more mine when there is not a good prognosis and we go in with the great guns and, you know, really aggressive and we see the patient failing. And I always felt that patient must realize that, you know, that we’re not really making headway here. And I’m always kind of surprised, but I guess not really, that, you know, that they’ll say, “I’ll try the second or the third treatment”, you know, when we do not have much to give them. (M)

Resolving conflicts

Participants described the approaches they take to try to resolve the conflicts. The primary approaches included strategies to obtain more information and understand the reasons for particular treatment choices as well as engaging in discussion and sharing patient perspectives with the physician.

I’ve never shirked from asking “why” and I don’t. My impression is that stuff here don’t shrink from asking “why”. I mean we haven’t been trained to defer. We consider ourselves to be partners and have questions. But when I’ve questioned physicians, particularly ones that I have worked with directly over the years, there has never been any difficulty with them saying “why” and sort of providing research background that led them to this conclusion, and then having a conversation with them about how the patient was doing on treatment...I think there needs to be more conversation between nurses and physicians about this kind of issue...Some physicians are really looking for that kind of input, depending on how they view their practice, and other physicians are assuming that they’ve made that assessment well. (I)

Well, we go back to the oncologist and we say how we feel. And of course, then he or she gives us their good reasons for treating and, you know, the patient has to buy into it. So if the patient had bought into it, what the oncologist has said, we have to buy into it, too. But, you know, it’s difficult. But there is always good discussion about it.
and they’re valid reasons. But still in your mind you sometimes think that this is all for naught. But certainly there is good discussion around it and try to feel better about it yourself, also. (M)

## Factors which help and hinder

Participants described factors in the work environment which they felt helped or hindered their ability to attend to issues of quality of life. These included factors concerning time to talk with patients, work environment structures which facilitate continuity, expectations of the nursing role, attitudes in the work setting, being able to build a relationship with patients and working with the patient as a partner.

...when patients come here for chemotherapy we actually sit down with them during the treatment whether it’s a 10-minute treatment or it’s a four-hour treatment. We’re here for them, whereas clinics can be busy and they’re rushed in and out. (B)

I’m in the room when we are dealing with a difficult situation, so that I know when they come back what support I need to give them. The doctor’s very upfront. He’s very honest. So in some ways I think that makes it easier...and the other thing I like about our practice is that family members are involved. I do the assessment, then he does the exam and then we all come back and sit together as a group. So then I know what’s going on and get a good feel for the family. (W)

In a primary nurse setting where you have a doctor and a nurse who have a group of patients, we get to know these people over time. It’s the continuity. They can always call you...There’s continuity which for me makes a big difference...you know what’s going on...you know what’s important...you see them more as people than bodies and beds. (A)

...I’ve noticed a change just coming here from the general hospital setting. It seems like quality of life is somewhat of an issue here. They look at the person’s well-being and their social support system to make sure the individuals are aware of the social services and social support to them along with home care, volunteer drivers to bring them to the clinic. I just sense a big difference from a large institution to here where it seems to be more of an issue here. (B)

...I think it depends on the physician involved in the patient’s care. I think there are physicians that are willing to look at the patient’s issues - emotional, physical, treatment-related. I think there are other physicians that do not feel that there’s a role for a lot of emotional support. And they are very treatment oriented and they really do not see a role. And I think that’s unfortunate. (P)

I think for nursing it’s a very difficult time right now because we’re under constant stress. And we’re trying to figure out a lot of things work-wise. It’s hard to concentrate on quality of life issues if your own quality of life isn’t where you want it to be. (G)

And you really get to know...you get to know pretty quickly what each patient, what they’re looking for...I think it’s because of this primary nursing. We see the patient at the beginning with the physician and you talk to them and you really establish a relationship...and we are involved in planning...and following the patient all the way through. (S)

I think the patient has to be able to keep some control to have quality of life. They have to participate in their care and they have to be a partner with us. (M)

## Summary

As I draw my remarks to a close, I will highlight what I learned from these data. Quality of life is central to the practice of oncology nursing. Even if oncology nurses are not using the language of quality of life, the focus of their practice is on quality of life issues.