Quality of Life Research, 5, pp. 5–14

Physicians' perspective on quality of life: An exploratory study of oncologists

K. M. Taylor*, K. G. Macdonald, A. Bezjak, P. Ng and A. D. DePetrillo

Department of Administrative Studies (K. M. Taylor, K. G. Macdonald); Department of Nursing (K. G. Macdonald); Department of Mathematics and Statistics (P. Ng) York University, North York, Ontario, Canada; Department of Radiation Oncology (A. Bezjak); Department of Surgical Oncology (K. M. Taylor, A. D. DePetrillo) Ontario Cancer Institute/Princess Margaret Hospital and University of Toronto, Toronto, Ontario, Canada

There is an implicit assumption that physicians incorporate quality of life (QOL) information in clinical decision-making. However, very limited data exists on how physicians view QOL information and how they actually use it. To explore this issue, an in-depth study was conducted using a semi-structured interview guide, with 60 oncologists in Canada and the USA. While the majority of respondents perceived QOL as important they reported a tendency to use it informally and not in all situations. Key findings include the belief expressed by 88% of respondents that the term QOL could be defined, although they differed in their definitions. Although 85% stated that QOL can be formally measured, only a third perceived that the current instruments provide valid and reliable data. Respondents noted a number of significant benefits and drawbacks of using QOL data in their clinical practice that had not been previously noted in the literature. For example, its use as an endpoint in clinical trials was generally perceived to enhance both physician and patient participation. A drawback noted was that including QOL might adversely affect the decision-making process. These findings have been used to develop a self-administered questionnaire (MD-QOL) which will test the generalizability of these findings.

Key words: Decision-making; oncology; physician behaviour; quality of life.

Introduction

Despite the apparent interest in the issue of quality of life (QOL) and its measurement in cancer[1–6] only limited attention has been given to whether or not QOL information is or will be used in medical decision-making. There are a few studies of how physicians define and interpret the term QOL, but almost no research that assesses their intention to use, or to disregard QOL information.[7–11] There is anecdotal evidence that little QOL information is currently being incorporated into decision-making and mounting concern whether it ever will be incorporated into routine cancer care.[12–15] QOL researchers are beginning to express their discomfort regarding the clinical relevance of their findings and whether or not QOL information will be ever useful in daily practice—their ultimate goal.[12,16–17] In fact, one of the most serious challenges will be to ensure that published QOL information will be appropriately utilized by practitioners, rather than remain in the domain of academic interest.[18–22]

Physicians are only recently gaining recognition as potential agents of change in such areas as QOL.[23–26] There has been an implicit but powerful belief that once conceptual and methodological obstacles were overcome, physicians would willingly incorporate QOL findings into routine treatment planning. At the same time, physician behaviour research in other areas suggests that this is unlikely.[27–30] For example, the physicians' response to QOL results may well be similar to their reluctance to incorporate into their practices the findings of randomized clinical trials (RCTs), where the excellence of the study design and the strength of trial results are necessary, but not sufficient, conditions to ensure change in physician behaviour.[31]

---

* To whom correspondence should be addressed at York University, Atkinson College, Department of Administrative Studies, K. M. Taylor, 4700 Keele Street, North York, Ontario, Canada, M3J 1P3.

To verify the anecdotal assumptions regarding the apparent reluctance of physicians to use QOL information, an exploratory study of physicians' attitudes and beliefs regarding QOL was conducted using cancer as a model. This was the initial stage in the development of an instrument to examine these issues in the larger physician population.

Methods

To obtain a better understanding of this complex issue, we conducted 60 in-depth semi-structured interviews with cancer physicians in Canada and the USA between October 1992 and April 1993. The interviews also covered physician perceptions regarding the patterns of practice in oncology, but this report focuses only on the considerable portion of the interviews that was devoted to the topic of physician views on QOL. Since it was impossible to identify *a priori* a unique profile of those physicians who use QOL from the literature or published physician directories, snowball sampling was considered the most appropriate means of collecting a rich data base from which key themes could be extracted.[32-36] An initial set of potential respondents was obtained from the oncological advisors to the project. Snowball sampling was then utilized to generate the sample frame. Respondents were randomly selected from this frame to be representative of the physician population by gender and specialty.[37-38] The final sample contains medical, surgical and radiation oncologists from all Canadian provinces and four regions in the USA. This strategy was devised to capture the heterogeneity of the three oncological specialties while ensuring the homogeneity of the respondents' core task—cancer patient care. The sample included oncologists who care for patients in all stages of their disease ranging from those who were currently disease-free to those in the chronic phase and to patients who were terminally ill. Both Canadian and USA physicians were included to account for the potential effects of differing health care systems. Of the 63 potential respondents approached, 60 agreed to participate within the time frame of the study.

The structured interview guide was designed to elicit how cancer physicians define and operationalize the term quality of life (QOL), how they use QOL information in their treatment decision-making and what their views are on the role of QOL in oncology. The structured interview guide consisted of open-ended and demographic questions (see Appendix 1). After a training session to ensure congruity between interviewers, the interviews were conducted by three of the research team members and by a professional interviewer. Sixty-eight per cent of the interviews were completed by telephone and 32% in person, and all were tape-recorded. The complete interviews, which lasted between 45 minutes and 2 1/2 hours, were transcribed verbatim. The data were then coded, grouped, quantified and analyzed by a researcher with extensive experience in analyzing qualitative physician behaviour data, using a rigorous grounded-theory content-analysis approach in the manner of Glaser and Strauss.[39-42] Extensive efforts confirmed the validity of initial findings firstly among the research team members and subsequently with other members of the target population.[7,9,11,43,44]

Results

The respondents were representative of the distribution of oncologists in terms of gender, age, income source and specialty.[37-38] The demographic profile of the respondents is summarized in Table 1. Overall, physician responses to all questions did not vary significantly by age, gender, practice setting or health care system.

Defining and measuring quality of life

Respondents were asked if the concept of QOL could be objectively defined. Eighty-eight per cent of respondents felt that QOL could be defined, while the remainder believed it was a fluid, changing, abstract concept. Despite the high proportion of respondents who believed the concept could be defined, interpretation of the term varied quite widely. For example, 65% emphasized the physical aspects of QOL, while 35% felt that non-physical elements such as emotional and psychosocial issues were most important. At the same time, 79% felt that both parameters contribute in varying degrees to an appropriate definition of QOL. Table 2 summarizes the components noted by physicians as critical to their definition of the concept of QOL.

Physicians were then asked what value they accorded QOL information and if they believed that QOL was a measurable concept. More than 90% believed that QOL was an important concept and 85% stated that QOL can be formally measured. Of those, 83% felt that QOL measuring instruments were only appropriate for use within randomized trials. With respect to the psychometric properties (i.e. the reliability and validity) of currently available QOL instruments, 34% perceived that the instruments

Table 1. Respondent demographics

Characteristics	% of Respondents (*n* = 60)
Gender	
Male	75
Female	25
Age (years)	
<45 yrs	48
≥45 yrs	52
Nationality	
Canadian	73
American	27
Country of training	
Canada	65
USA	25
Other	10
Oncology specialty	
Surgical	43
Medical	35
Radiation	22
Patient population	
Mainly cancer	67
Mixed	33
Primary time allocation	
Patient care	75
Administration	14
Research	9
Teaching/Other	2
Income source	
Fee for service	56
Salaried	44
Practice setting	
University hospital	60
Community hospital	25
Private practice	15

generally provide valid information and 39% believed that the data they provide are reliable. Of those who stated that QOL cannot be measured at this time, 55% believed that appropriate QOL measures would eventually be developed.

Acquiring and using quality of life information

Approximately two-thirds of respondents reported that, in their setting, both formal and informal QOL data collection was done by non-physicians. When asked about their use of QOL information, 52% stated that they were more likely to use QOL when they worked as part of a cancer care team than when they acted as solo practitioners. Thirty-five per cent reported that while a team approach may enhance their use of QOL information, it may also result in group-based decisions that may be insensitive to individual patient needs.

Table 2. Oncologists' definition of the concept of QOL

Definitions	%of Respondents who included this term (*n*=60)*
Patients' sense of well being	89
Patients' performance status	76
QOL is an ill defined concept	71
Patient satisfaction with their current status	54
Related to impact of treatment	48
Related to effects of disease	35
Defined by cultural expectations	21

*Note that most respondents included more than one descriptor when defining QOL

Only 7% of respondents stated that they formally both collected and used QOL information. In contrast, 68% of respondents reported that they neither collected nor formally integrated QOL information into their individualized decision-making, although many used it informally and considered it in their global approach to patient care. Although 11% stated that they had formally collected QOL data as part of an RCT, many were concerned that the data may not be generalizable to their personal patient population and therefore did not formally integrate it into their practice. On the other hand, 14% of the respondents stated that while they have not collected QOL data themselves, they routinely use published QOL results in discussion with their patients.

Shared decision-making between physician and patient was described as the ideal model for incorporating quality of life information into the treatment decision-making process according to 67% of respondents. However, half of those respondents alluded to a difference between the actual and perceived sharing of the decision. Fourteen per cent of the 60 respondents felt strongly that oncologists should maintain control of QOL decision-making based on their belief that as physicians, they had the appropriate distance and insight into the relative overall importance of QOL. In contract, 17% of physicians felt that the patient should have ultimate responsibility for the way in which QOL information is used. However, 12% believed that giving this responsibility to patients was not always positive. They felt that this may cause some patients to doubt the choices had been made—perhaps by inappropriately having traded increased survival time for improved QOL.

Consequences of using quality of life data

Respondents had mixed responses regarding actual and potential repercussions of incorporating QOL into individual decision-making. More than half (54%) considered published QOL information as clinically relevant at this time. While a slight majority (58%) believed that including QOL makes clinical decision-making more difficult, 32% believed including QOL makes it easier and 10% perceived inclusion would have no effect on physician decision-making. It is interesting to note that the majority of respondents (78%) believed that their patients want to be informed regarding QOL issues but still prefer that their physician take responsibility for the final decision. Although 47% of the physicians felt that discussing QOL issues had no obvious impact on the patient, 24% felt that it puts too much pressure on them while 29% felt that discussing QOL issues makes the patients feel that they are part of the team.

Specific positive and negative consequences of incorporating QOL into decision-making were noted. For example, 81% of respondents thought that discussing QOL reassured patients that their doctors care about them, not just their disease. Of note, however, 74% of respondents expressed concerns that patients would interpret a discussion about QOL as meaning that survival was no longer a consideration. Perceived benefits of using QOL information included allowing for comparisons between treatments of similar efficacy (mentioned by 61% of respondents), and supporting the decision not to use toxic treatments that provide minimal survival advantage (53%). Drawbacks included difficulties in the following: incorporating QOL in individual clinical practice especially in view of the time constraints (85%); maintaining neutrality (67%); and the overriding importance of survival (46%).

There was almost universal consensus (91%) on the usefulness of QOL information in palliative settings. In situations physicians perceived as potentially curative, many respondents (59%) said they encourage patients to tolerate decreased QOL during treatment in exchange for chances of increased survival. Forty-three per cent stated that their focus was on survival rather than QOL because they believed that, generally, patients are more concerned about length rather than quality of their survival. A similar proportion (46%) stated that when treating patients with curative intent, QOL should always be the secondary, not the primary goal, since the main task of physicians is to save lives.

Oncologists were asked for their opinion on QOL as an endpoint in randomized clinical trials (RCTs). There was a divergence of responses with respect to the relative values of QOL and survival as primary outcome measures. Some (56%) maintained that survival has been, and should remain, the primary outcome measure in RCTs in oncology. They argued that QOL becomes irrelevant if survival can be guaranteed. At the same time, 76% felt that QOL is the more meaningful goal for RCTs. They maintained that physician participation in RCTs would be enhanced if QOL is added to survival as an outcome measure. In addition, they believed that adding QOL as an endpoint would encourage more patients to participate in randomized trials. Forty-three per cent of those interviewed noted that RCTs are used to educate and therefore, including QOL assessments in RCTs may convince some physicians of the credibility of QOL data.

Discussion

There was considerable variation in attitudes towards measuring QOL and incorporating this information into patient management. Most respondents felt that QOL can be defined and measured, but the majority questioned the reliability and validity of existing quality of life instruments. It may be of value to know if familiarity with QOL would increase, or decrease physicians' willingness to use the ensuing data.

Defining and measuring quality of life

Although some respondents felt quality of life cannot be defined, their reported behaviour was similar to the majority of respondents who felt that quality of life can be defined. That is, they reported assessing and using QOL informally, although they maintained they could only describe QOL using vague and subjective terms. One of these respondents explained:

> "I think it is hard to define because what is QOL for one person is different for the next. It is a grey zone term, but I think as physicians we talk around QOL, so that you at least imply a meaning—it is satisfaction, mood, that sort of thing."

Other respondents stated that QOL could indeed be defined, but that it was complex and multi-faceted. One such respondent explained:

> "I guess it really has to do with control of the symptoms related to the disease. The goal is to maximize the patients' ability to function at home

> so that they are with their family. Their comfort and activity level is the primary definition of QOL."

In another example, a medical oncologist reported:

> "It is a relative term that means how well satisfied the patients are with their health status; it is a relative term in that it is usually measured against what their expectations are so it may in fact measure the distance between what their expectations are and what reality is. The smaller the distance, the higher the quality of life. The expectations are usually culturally defined and therefore vary among and between patients."

There was considerable variation in the responses regarding the key components of QOL, and respondents emphasized a range of parameters. Although the majority of respondents felt that performance status is an important aspect of QOL, only half also considered the effect of treatment on emotional, psychological and social well-being. Even fewer considered the effects of the disease and/or its treatment on QOL.

Despite the fact that physicians may agree that QOL is an important concept, their apparent disagreement on the definition of the term may well be problematic in incorporating its use. Evaluating QOL as important, but disagreeing on the meaning and implications of the term may well be a deterrent to its use. The validity and reliability of current QOL data were also questioned by many respondents. One surgeon explained:

> "I do not think QOL data so far are valid. It is a very personal thing and cannot be quantified or compared. It is like falling in love—you know it happens, but can you really quantify it and then compare experiences—no, you would be laughed at for even thinking about trying. I feel the same way about QOL data."

A radiation oncologist stated:

> "I think they are as reliable as you can get in a very difficult area, but they are not really what I would call reliable. For example, I think that a lot of measurements are aimed at looking at subjective measurements, not objective. My definition of a scientific parameter is that it has a certain objectivity built in, but how do you do that with QOL?"

The lack of consensus on a definition and assessment of the level of measurability of the term QOL may account for a portion of the reported diverse physician behaviour regarding QOL. For example, performance status was often used to define QOL, and the terms were sometimes used synonymously. The emphasis on the interpretation of QOL in terms of performance status may have several causes. First, it is a term that is more concrete, more easily and quickly measured and it may be more familiar to oncologists. It is a generally accepted prognostic factor in clinical practice and a common inclusion/exclusion criterion in randomized clinical trials. Studies show considerable inter-observer variability in assessing performance status, thus raising serious questions regarding the reliability of these measures.[45–47] Nonetheless, respondents were more convinced of the clinical relevance of performance status rather than of QOL. Quality of life was generally seen as the more subjective and less relevant term.

Many of the interviewed oncologists emphasized the physical rather than the psycho-social domain of QOL, including symptom control and toxicity of treatment. They felt that this was of primary importance in QOL measurement. This appears to contrast with the approach taken by many cancer cooperative research groups, where symptom control and QOL are often distinct areas of discussion and research. The respondents' emphasis on symptom control appears to be related to their comfort with the numerous clinical interventions and measurement tools developed in the physical domain which they believed contrast with the limited number of instruments and experiences with non-physical domains.

In summary, despite the vagueness of the concept of QOL, the majority of the respondents felt that it can be measured, although two-thirds of respondents perceived that the current measures are neither valid not reliable.

Acquiring and using quality of life information

Oncologists differed on whether they acquired and/or used QOL information. Some respondents were willing to collect QOL, but only as part of RCT requirements and were not willing to use published QOL data in their practice. Others were not willing to collect QOL, but were willing to use published information in their practice. This apparent dichotomy raises interesting questions since several research groups have assumed that those physicians willing to collect QOL information are more likely to be those who use it. Our data suggest that this assumption should be explored more carefully.

Many oncologists interviewed neither collected nor formally used QOL information. They said that they relied on their informal assessments of QOL, and informally incorporated their impression of patients' desires regarding QOL into their decision-making. Many stated that this was an acquired skill, following years of medical practice, and was a key component of the 'art of medicine'. If physicians believe that evaluating QOL should be based on interactions between individual physicians and their patients, data gathered from other patients would not likely be seen as useful. In instances in which QOL is a consideration, two-thirds of respondents described a shared decision-making process with input from both patient and family as well as the medical team. The interviews revealed some of the complexities of this process, especially when the initial preferences of patients and physicians differ. The therapeutic decision in that case may be reached by one party convincing the other of its preference, or by one party exerting control despite the other party's opposing view. The interview data strongly suggest that many physicians perceive themselves, rather than their patients, as being entitled to ultimate control over the treatment decision on such a situation.

Consequences of using quality of life data

Clinical relevance. Only a few respondents interpreted QOL as having clinical relevance for individual decision-making at this time. A typical response is reflected in these statements:

> "It is only clinically relevant if you can provide an intervention on the patient's behalf that would improve the problems you detect with your instrument in terms of QOL. If you cannot do this, then simply measuring QOL is not relevant. If helping to improve the patients' QOL means additional time for the physician, I do not think it will ever be really clinically relevant. For example, if improving QOL for terminally ill patients means good hospice services, providing home care and so forth. When you do that it makes more work for the physician. It involves many more phone calls and none of that is reimbursed."

If respondents do not believe that QOL information is clinically relevant, it appears unlikely that it will be easily incorporated into routine practice. Perhaps QOL researchers developing QOL instruments should consider the perceived clinical relevance of the data they are collecting as part of their instrument development. Designing excellent instruments with strong psychometric properties may be necessary, but not sufficient to guarantee their incorporation into medical practice—the ultimate goal.

Another focus of the discussion of the clinical relevance of QOL related to the use of QOL in curative vs. palliative settings. Many argued that QOL was most, and sometimes only, useful in palliative settings. One medical oncologist explained:

> "The average patient with cancer, if you are offering a treatment and explaining to them what the anticipated results are, sure they want to know the side effects of the treatment. But, they don't really see this as a quality of life issue. Really, they want to know is what is chance they will be cured, or that the treatment is going to work. The side effects—they will put up with those."

At the same time, the QOL literature does not generally relegate QOL discussions to palliative settings only. This discrepancy may account for the apparent disparity between the objectives of QOL instrument designers and those reluctant to use them for early stage disease (potentially curable) patients. Another area of contention for respondents was whether they made decisions with or for their patients. The potential for QOL to facilitate or to impede the type of decision-making models physicians prefer, may also have an impact on their willingness to use this information. For example, one physician explained:

> "We recently had a patient who went for a bone marrow transplant even though I was skeptical because she decided that the treatment would increase her chances of having a good quality of life as well as improving her survival odds. That is very experimental treatment in ovarian cancer in the States, and she came back looking wonderful at the moment. She'll die from her disease almost certainly, but nevertheless she is getting something out of it. I recently said to her 'I have a patient who is facing the same thing as you and wants to talk to someone. Would you be willing to meet her?' She said 'Of course, but don't forget I'll tell her that if I had to do it over again, I would not.' Those kinds of comments from a very reliable and credible witness, it really makes you sit up and take notice. It reminds me that it is my job to protect the patient from things they can't really decide on their own so occasionally I become very autocratic. I try very hard to avoid the autocratic role, but sometimes I think I should do it more often."

It was interesting to note that some respondents were supportive of the clinical relevance of QOL data, but did not see the incorporation of QOL as truly a part of their core task—rather they interpreted it as more essential for related health care providers such as nurses. If physicians interpret QOL as 'interesting' but not their responsibility, will QOL results be relegated to ancillary, rather than primary components of cancer care? One respondent said:

> "Nurses appreciate things about how patients are feeling that a physician does not because they are working with them more closely on a day to day basis. Patients often seem more comfortable talking with nurses. They have the time, they sit down and listen to the patient, even on a busy clinic day. They often give us physicians information and then we change our minds."

Many oncologists interviewed acknowledged that the published QOL results were particularly difficult to adapt for individual practice. Reasons given included: individuality of response to treatments; the perception that patients may feel abandoned if physicians emphasize QOL; the time and skill required to adequately assess and evaluate published QOL data; and physician scepticism regarding the face validity of patient responses to QOL questions. These rationales were expressed by physicians to support their reluctance to use QOL data in their practice at this time.

QOL and decision-making. The majority of respondents felt that it is difficult to include QOL in clinical practice. Rather than facilitating decision-making, most respondents argued that it makes decision-making harder. One respondent stated:

> "I'm sure a lot of physicians will say that they always include quality of life considerations in their decisions and that not to do it would sound like they were callous or something. But let me tell you the way it is. It actually makes many of relationships with patients much more difficult. It sure takes more time. Instead of having a single answer for everybody, if you really try to interpolate the detail that you could learn about the person's life style, their desires and their wishes, their dreams and what they secretly hope, then dealing with them becomes very complicated and not a fast process by any means. I think any time that you try to change what you do based on changeable things like patients' perceptions of their QOL and then try to help them incorporate it into their decision-making well, I think you stop practising cancer medicine and start doing psychotherapy and that's not my job!'

Unless physicians can see a benefit to incorporating QOL in treatment decision-making, it is likely that they will resist including what they interpret as a hindrance to an already arduous task. Few respondents systematically and formally collected and utilized QOL information in their practices. Of those who did, the majority had other, non-physician health personnel collect the data. This may have significant implications for the doctor–patient relationship. Some physicians felt that certain generic QOL instruments were inappropriate for many ethnic groups. Others believed that asking patients to complete QOL questionnaires often provoked anxiety in patients, regardless of their cultural background. It was interesting to note that the formality of the QOL instrument was seen, by some respondents, as potentially distancing the physician from their ability to intuitively assess the patients' well-being.

The informal collection and use of QOL data was perceived by many respondents to be a better means of understanding individual patient needs and indeed was seen as an integral part of the innate 'art and craft' that contributes to the professionalism of a medical practice gained over years of experience. Physicians' opinions on the advantages and disadvantages of using QOL information tended to focus on the formal collection and use of QOL data rather than the informal. In an economic environment where rationing of services is an important component of clinical practice, the formal use of QOL was described by some respondents as a way to support the most fiscally responsible medical decisions. In addition, they argued that it was an effective mechanism to defend decisions not to use aggressive and expensive treatments that cause marked decrease in QOL for potentially minimal survival improvements.

Randomized clinical trials: Applying QOL data obtained from RCTs. Most respondents felt that QOL can and should be measured only within randomized clinical trials. This rationale may help them to justify their concern regarding the lack of clinical relevance of QOL data, while at the same time permitting them to state that the concept itself was of importance. A sizeable proportion (38%) were not supportive of QOL information, even in the context of RCTs which raises the question of whether even apparently committed oncologists will apply QOL data from clinical trials into practice. One explained:

> "I only collect the information when I'm asked to do it in a clinical trial setting, but to be honest I find it very time consuming. It is especially hard

> since we don't act on any of the results—we just collect piles and piles of information. No, to be very honest, I don't use it on my non-trial patients. I'd have to ask my patients how they are feeling all the time, comparing little day-to-day variations. I don't think that is the best use of my time."

Another concern expressed regarding QOL was that of generalizability vs. specificity of the instruments. While QOL data collected from clinical trials was perceived as useful in assessing the overall value of promising but untested interventions, most physicians agreed that the data were not specific enough for individualized care. Since many variables enter into the cost/benefit analysis (including both duration and quality of life), QOL data collected from clinical trials was generally perceived as not yet being applicable in individual cases.

QOL and participation in RCTs. There was a dichotomy of opinions regarding the effect of QOL assessment on participation in clinical trials. Although most of the respondents felt that QOL is an important endpoint of RCTs in oncology and that patients would be more willing to participate in trials that assess QOL, others expressed concern that physician participation may be discouraged if QOL replaces survival as an outcome measure. One surgeon emphatically suggested:

> "I think that QOL will encourage more physicians to put patients on trials. I think this is particularly true in settings with non-curative treatments because often what you are left with at the end of the day is essentially a trial that shows no clear cut advantage to one therapy over another. In that case, I think it is clearly very important to have a quality of life information. In the practical world of decision-making you want to know if a treatment is in fact going to help in terms of tumour regression, but is tolerable in terms of symptoms. You need both pieces of information."

QOL as an outcome measure in RCTs. Many respondents believed that QOL is the more meaningful goal for clinical trials, since prolonging survival with poor QOL is not a success. One physician explained:

> "Complicated cure—that's what cancer really is. The vast majority of the time, you don't cure it. Really it is palliative treatment no matter how we like to fool ourselves and pretend it isn't. If it's palliation, then you should abide by the rules. Palliation means control of symptoms to improve quality of life. It does NOT mean extending life for an extra two or three days or a month, it means focusing strongly on QOL. QOL is, or at least in my opinion should be, the main issue in most randomized clinical trials. These cases, unfortunately, represent the bulk of our work and this should be acknowledged by having QOL as a trial outcome. Not to do that is only fooling ourselves into believing that survival is really an endpoint."

Our interview data support the recent ECOG study in which 89% of the 1800 respondents selected QOL over survival as the more significant trial end-point.[11] This reflected in the increasing numbers of RCTs where a QOL outcome measure is now included as a central rather than ancillary outcome criterion.

Implications

Research regarding physician interpretation of QOL information and assumptions regarding their willingness to use it, has generally been restricted to two important but somewhat narrowly defined aspects. The first is the physicians' role in the palliative care of patients with advanced disease. The second is the incongruence between the patients' and the physicians' assessment of quality of life. This has encouraged many QOL researchers to argue for a patient-centred measuring instrument. Although the physicians' and patients' perspectives may not coincide, this does not imply that physicians will not be the key agents of change. Thus, an in-depth understanding of their perspective will greatly improve the chance that the QOL information will be used effectively by physicians and their patients. This exploratory study was intended to gather an information-rich data base from which key issues could be extracted to provide the basis for a self-administered questionnaire. The findings were tested for face validity through peer-reviewed presentations to several oncology groups.[7,9,11,43,44]

The research confirmed some significant anecdotal assumptions regarding physician use of QOL as well as raising new questions that must be addressed as soon as possible. Using these study results, an instrument to assess physician willingness to use QOL data (MD-QOL) has been developed to test the generalizability of these initial findings.

References

1. Cella DF, Tulsky DS. Measuring quality of life today. *Meth Aspects Oncol* May 1990; **4**: 29–38.
2. Aaronson NK. Quality of life research in cancer clinical trials: A need for common rules and language. *Oncol* May 1990; **4**: 59–66.
3. deHaes JCJM, Knippengurg V. The quality of life of cancer patients: A review of the literature. *Soc Sci Med* 1985; **20**: 809–817.
4. Osoba D. Lessons learned from measuring health-related quality of life in oncology. *J Clin Oncol* 1994; **12**: 608–616.
5. Nayfield S, Ganz PA, Moinpour CM, *et al.* Report from a National Cancer Institute (USA). Workshop on Quality of Life Assessment in cancer clinical trials. *Qual Life Res* 1992; **1**: 203–210.
6. Berzon RA, Simeon GP, Simpson RL, Tilson HH. Quality of life bibliography and indexes—1992 update. *J Clin Res Drug Develop* 1993; **7**: 203–242.
7. Taylor K, DePetrillo D, Macdonald K, *et al.* Quality of life information: How do/would oncologists use it? *Proc Annu Meet Am Soc Clinic Oncol.* Orlando, USA 1993; **12A**: 1573.
8. Taylor K, Bezjak A, Macdonald K, *et al.* Oncologists' use of quality of life information: Implications for cancer supportive care. *Proc 6th Int Conf Supportive Care.* New Orleans, LA, USA 1994.
9. Taylor K, Bezjak A, DePetrillo AD, Macdonald K. Attitudes of oncologists to quality of life measurement. *Clinical Trials in Oncol Conf.* Toronto, Canada 1993.
10. Taylor K, Ng P, Macdonald K, Bezjak A, DePetrillo D. Developing a measuring instrument to assess physician use of QOL information. *Clin Invest Med* August 1994; **17**: B88.
11. Taylor K, Bezjak A, DePetrillo D, Macdonald K. Collecting quality of life information: Does it facilitate or impede physician accrual to randomized clinical trials? *Int J Gyn Cancer* 1993; **3 (Suppl 1)**: 44 (abstract 159).
12. Lohr KN. Applications of health status assessment measures in clinical practice. *Med Care* May 1992; **Suppl MS**: 1–14.
13. Till JE, Osoba D, Pater JL, Young JR. Research on health-related quality of life: Dissemination into practical applications. *Qual Life Res* 1994; **3**: 279–283.
14. Cella D, Tulsky DS. Quality of life in cancer: Definition, purpose and method of measurement. *Cancer Invest* 1993; **11**: 327–336.
15. Meyerowitz BE. Quality of life in breast cancer patients: The contribution of data to the care of patients. *Eur J Cancer* 1993; **28A (Suppl 1)**: S59–S62.
16. Van Dam FS, Linssen CA, Couzijn AL. Evaluating quality of life in cancer clinical trials. In: Buyse ME, Staquet MJ, Sylvester RJ (eds) *Cancer Clinical Trials Methods and Practice.* New York: Oxford University Press, 1984: 26.
17. Slevin ML. Quality of life: Philosophical question or clinical reality? *Brit Med J* 1992; **305**: 466–469.
18. Aaronson NK, Meyerowitz BE, Bard M, *et al.* Quality of life research in oncology: Past achievements and future priorities. *Cancer* 1991; **6 (Suppl 3)**: 839–843.
19. Lomas J. Words without action? The production, dissemination and impact of consensus recommendations. *Ann Rev Pub Hlth* 1991; **12**: 41–66.
20. Drummond MF. Resource allocation decision in health care: A role of quality of life assessment? *J Chron Dis* 1987; **40**: 605–616.
21. Reynolds T. Quality of life adds a human dimension on treatment cost-effectiveness. *J Natl Cancer Inst* May 4, 1994; **86(9)**: 661–662.
22. Till JE. Uses and some possible abuses of quality of life measures. In: Osoba D, ed. *Effect of Cancer on Quality of Life.* Boca Raton, FL, USA: CRC Press, 1991: 137–154.
23. Taylor KM, Feldstein ML, Skeel RT, Pandya K, Ng P, Carbone P. Fundamental dilemmas of the randomized clinical trial process. Results of the 1737 Eastern Cooperative Group Investigators. *J Clin Oncol* 1994; **12**: 1796–1805.
24. Light D, Levine S. The changing character of the medical profession: A theoretical overview. *Milbank Quarterly* 1988; **66(Suppl 2)**: 10–31.
25. Coburn D. Canadian medicine: Dominance or proletarianization? *Milbank Quarterly* 1988; **66(Suppl 2)**: 92–117.
26. Duran-Arenas LB, Kennedy MC. The constitution of physicians' power: A theoretical framework for comparative analysis. *Soc Sci Med* 1991; **32**: 643–648.
27. Taylor K. Integrating conflicting physician roles: Physician participation in randomized clinical trials. *Soc Sci Med* 1992; **35**: 217–224.
28. Taylor K, Macdonald K, Ng P, Bezjak A, DePetrillo D. The black box: Physician response to cancer guidelines. *Can J Oncol* 1995 (in press).
29. Macdonald K. *Adoption of Health Care Innovations by Canadian Physicians.* Ottawa, Canada: Micromedia Ltd., 1992.
30. Harris JS. Why doctors do what they do: Determinants of physician behaviour. *J Occup Med* 1990; **32**: 1207–1220.
31. Taylor K, Margolese R, Soskolne C. Physicians' reasons for not entering eligible patients onto randomized clinical trials for breast cancer. *New Eng J Med* 1984; **310**: 1372–1376.
32. Denzin NK, Lincoln YS. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage Publications, Inc., 1994.
33. Kuzel AJ. Sampling in qualitative inquiry. In: Crabtree BF, Miller WL, eds. *Doing Qualitative Research* Research Methods for Primary Care Series, Vol 3. Newbury Park, CA: Sage Publications, Inc. 1992: 31–44.
34. Miles MB, Huberman AM. *An Expanded Sourcebook: Qualitative Data Analysis (2nd ed).* Thousand Oaks, CA, USA: Sage Publications, Inc. 1994.
35. Patton MQ. *Qualitative Evaluation and Research Methods (2nd ed).* Newbury Park, CA, USA: Sage Publications, Inc. 1990.
36. van Meter KM. Methodological and design issues: Techniques for assessing the representatives of snowball samples. *NIDA Research Monograph* 1990; **98,51.40**: 31–43.
37. American Society for Clinical Oncology. *ASCO Membership Directory* 1992.
38. *Annual Directory of Canadian Physicians.* Toronto, Canada: Southam Press, 1992.
39. Glaser BG, Strauss AL. *The Discovery of Grounded Theory.* New York: Aldine Publishing Company, 1967.
40. Glaser BG. *Emergence Versus Forcing: Basics of Grounded Theory Analysis.* Mill Valley, CA: Sociology Press, 1992.
41. Firestone WA. Alternative arguments for generalizing from data as applied to qualitative research. *Educ Res* 1993; **22**: 16–23.
42. Strauss A, Corbin J. *Basics of Qualitative Research: Grounded Theory Procedures and Techniques.* Newbury Park, CA, USA: Sage, 1990.
43. Taylor KM, Macdonald KG, Nicholson J, *et al.* Quality of life information—How do/would oncologists use it in treatment planning. *4th Int Conf on Chemotherapy.* Paris, France 1993.

44. Taylor KM, DePetrillo AD, Macdonald KG, *et al.* Quality of life or survival as the key endpoint in randomized cancer trials—The oncologist's view. *Soc for Clin Trials.* Orlando, FL, USA 1993.
45. Mor V, Laliberte L, Morris JN, Wiemann M. The Karnofsky performance status scale: An examination of its reliability and validity in a research setting. *Cancer* 1984; **53**: 2002–2007.
46. Schag CC, Heinrich R, Ganz PA. Karnofsky performance status revisited: Reliability, validity, and quidelines. *J Clin Oncol* 1984; **2**: 187–193.
47. Bruner DW. In search of the 'quality' in quality-of-life research. *Int J Radiation Oncol, Biol Phys.* 1995; **31**: 191–192.

Appendix 1: Interview guide summary*

Traditionally, patient survival has been the key endpoint guiding the professional activities of most cancer physicians. While quality of life was always a consideration, patient survival was often defined as ***the*** primary goal.

Since few significant advances in cancer treatment are leading to meaningful increases in patient survival, some physicians have begun to explore the role of patients' quality of life. This is raising many interesting discussions.

Defining, measuring and using quality of life information: Some doctors believe that the term quality of life cannot be ***defined***. Do you agree? How would you define it? Some believe that quality of life cannot be ***measured***. Do you agree? Is the current information on quality of life generally reliable/valid? If quality of life data was totally ***convincing*** (to you) would you use it? How?

Formal or informal use of quality of life measures: Are you currently using formal quality of life measures? If yes, how? If not, are you using quality of life informally? Can you give examples? With regard to making treatment decisions is QOL relevant and does it: (1) help; (2) make it more difficult; (3) make no difference?

Risks/benefits of using quality of life information: What are the risks (drawbacks) and what are the benefits of including quality of life in treatment planning for cancer patients? Can you identify some? Can you give an example?

Quality of life and advancing science: Some physicians argue that if enhancing quality of life ***replaces*** extending patient survival as the primary outcome measure, it will be more difficult to advance science through clinical trials. Others argue that by ***adding*** quality of life as an outcome measure to RCTs, physicians and patients will be ***more*** willing to participate. Do you agree with either hypothesis? Why? or why not? Can you think of some specific examples?

Responsibility for quality of life: Whose viewpoint should carry the most weight in determining the relative importance of quality of life (e.g. the physician of record, the other health care professionals, the patient, the family members) in treatment planning? Some groups' views on quality of life sometimes conflict (e.g. in a particular case a physician may have a different opinion from the patient, their family, the nurse)? Have you ever observed such a quandary? How was it resolved?

Controversy A: What do ***you do*** when you know that your patients' chances for increased quality of life can only come with decreased chances of survival? What if increased survival can be gained only with decreased quality of life? Does this happen frequently?

Controversy B: Some oncologists treat advanced cancer patients who have little or no chance of any meaningful survival. They have told us that even when they fully explain to their patient that treatment will be ineffective and will likely decrease the quality of their remaining life, many patients insist on being treated aggressively. Can you explain this? Has this ever happened to you? What did ***you do***?

Controversy C: Some oncologists have told us that they occasionally convince a patient to continue on a protocol that they know is decreasing their quality of life so that information on the benefits/drawbacks of the treatment can be collected and used to help others. Can you elaborate? Have you or someone you know ever done this? What were the circumstances?

(Received 25 February 1995; accepted 8 August 1995)

---

* excluding demographics