EUROPEAN JOURNAL OF CANCER 45 (2009) 2510–2518

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Patients' and health care professionals' evaluation of health-related quality of life issues in bone metastases

Kristin Harris[a], Edward Chow[a,*], Liying Zhang[a], Galina Velikova[b], Andrea Bezjak[c], Jackson Wu[d], Michael Barton[e], Orhan Sezer[f], Richard Eek[g], Jesmin Shafiq[e], Albert Yee[h], Mark Clemons[i], Michael Brundage[j], Peter Hoskin[k], Yvette van der Linden[l], Colin D. Johnson[m], Andrew Bottomley[n], on behalf of the EORTC Quality of Life Group

[a]Department of Radiation Oncology, Odette Cancer Centre, University of Toronto, Sunnybrook Health Sciences Centre, 2075 Bayview Avenue, Toronto, Ontario, Canada M4N 3M5
[b]Cancer Research UK Clinical Centre, University of Leeds, St. James's University Hospital, Leeds, UK
[c]Department of Radiation Oncology, Princess Margaret Hospital, University Health Network, University of Toronto, Toronto, Ontario, Canada
[d]Department of Radiation Oncology, Tom Baker Cancer Centre, University of Calgary, Calgary, Alberta, Canada
[e]Collaboration for Cancer Outcomes Research and Evaluation (CCORE), Liverpool Hospital, Liverpool, NSW, Australia
[f]Charité, Universitätsklinikum Berlin, Germany
[g]Borden Medical Oncology, University of New South Wales, Sydney, New South Wales, Australia
[h]Department of Orthopaedic Surgery, Sunnybrook Health Sciences Centre, University of Toronto, Toronto, Ontario, Canada
[i]Division of Medical Oncology, Princess Margaret Hospital, University Health Network, University of Toronto, Toronto, Canada
[j]Department of Radiation Oncology, Kingston Regional Cancer Centre, Kingston, Ontario, Canada
[k]Mount Vernon Hospital, Northwood, Middlesex, UK
[l]Radiotherapeutic Institute Friesland, Leeuwarden, The Netherlands
[m]University Surgical Unit, Southampton General Hospital, UK
[n]European Organization for Research and Treatment of Cancer, Brussels, Belgium

ARTICLE INFO

Article history:
Received 30 March 2009
Received in revised form 11 May 2009
Accepted 15 May 2009
Available online 25 July 2009

Keywords:
Bone metastases
Health care professionals
Health-related quality of life
Patients

ABSTRACT

The objective of this study was to examine the agreement between health care professionals' (HCPs) and patients' evaluation of health-related quality of life (HRQOL) issues for cancer patients with bone metastases. A total of 413 patients and 152 HCPs were interviewed across five centres worldwide. Mean scores were almost always higher for HCPs than for patients. Patients and HCPs agreed that four issues affect HRQOL of bone metastases patients profoundly: 'long-term (chronic) pain', 'difficulty in carrying out usual daily tasks', 'able to perform self-care' and 'able to perform role functioning'. A substantial difference was found with respect to the perceived importance of psychosocial and somatic issues. Patients emphasised psychosocial issues with a particular focus on 'worry' about loss of mobility, dependence on others and disease progression, HCPs however rated 'symptom' issues as more important, specifically those related to 'pain'. In conclusion, patients and HCPs agreed that pain and physical/role functioning are important to the HRQOL of cancer patients with bone metastases, but patients also emphasized the importance of psychosocial issues to HRQOL. This information

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* *Corresponding author*: Tel.: +1 416 480 4998; fax: +1 416 480 6002.
E-mail address: Edward.Chow@sunnybrook.ca (E. Chow).

doi:10.1016/j.ejca.2009.05.024

has been an important component in the development of a health-related quality of life questionnaire for patients with bone metastases (EORTC QLQ-BM 22).

1. Introduction

Health-related quality of life (HRQOL) is a multidimensional construct that encompasses domains such as general health, physical symptoms, physical functioning, emotional well-being, cognition, role functioning, social well-being, sexual functioning and spirituality.[1,2] HRQOL has been shown to be a strong prognostic variable and can be especially important in guiding treatment decisions when alternative approaches demonstrate similar survival outcomes.[3–5] Patients are the best judges of their own HRQOL,[6] and correspondingly, HRQOL instruments increasingly recognise the importance of patients' perspective.

Patients with bone metastases experience their own distinct symptoms and emotional issues when facing advanced cancer and its treatment. While pain is the most common symptom reported by bone metastases patients, it is not yet clear what factors most strongly influence the HRQOL of these patients.[7] Barton and colleagues[8] conducted a literature review and interviewed patients on what they perceived as the most important HRQOL outcomes of radiotherapy for bone metastases. They confirmed that the impact of metastatic disease and radiotherapy extends well beyond pain. The patient's quality of life is affected by many other factors; including limited mobility, reduced performance, treatment side-effects and impaired role functioning.[8] This study is of valuable contribution to the effort of determining which end-points are most important in evaluating patients' HRQOL, however it must be considered that this work was completed nearly ten years ago and patients' preferences may no longer be comparable. No study to date has examined HRQOL outcomes from the health care professional's (HCP) perspective or with a large population of patients at various stages of their metastatic illness.

Despite the abundance of research in the management of bone metastases, a well-developed disease-specific patient HRQOL instrument was lacking. In collaboration with the European Organization for Research and Treatment of Cancer (EORTC), our team has developed a HRQOL module specific to cancer patients with bone metastases (EORTC QLQ-BM22) that will supplement the EORTC HRQOL core questionnaire for cancer patients (EORTC QLQ-C30).[9] The data collection associated with developing this international HRQOL assessment tool provided the opportunity to draw from a large sample of patients and HCPs and conduct an in-depth analysis of their evaluation of different HRQOL domains and specific items of cancer patients with bone metastases.

2. Methods

A list of 61 HRQOL issues was developed from an extensive literature search and preliminary interviews with patients and HCPs in developing the EORTC quality of life questionnaire for patients with bone metastases (EORTC QLQ-BM 22).[9] The list was grouped into six themes: symptoms (13 items), function (15 items), side-effects from treatment (3 items), psychosocial (27 items), treatment expectations (2 items) and others (1 item). These items were formatted into a questionnaire which was administered to patients with bone metastases at five centres: Odette Cancer Centre (OCC), Toronto, Ontario, Canada; Princess Margaret Hospital (PMH), Toronto, Ontario, Canada; Tom Baker Cancer Centre (TBCC), Calgary, Alberta, Canada; Liverpool Hospital, Liverpool, New South Wales, Australia; and Charité Hospital (Universitätsmedizin Berlin), Berlin, Germany.[10] For the Charité Hospital in Berlin, the questionnaire was translated into German according to EORTC translation guidelines. Questions 43 and 57 were altered and question 58 was excluded because of ethical considerations. The translation was used for both patients and health care professionals.

Patients over the age of 18 years with radiographic evidence of bone metastases were eligible to participate regardless of their primary cancer site, gender or treatment modality. Patients were required to speak and read English in Canada and Australia, and were required to speak and read German in Germany. Participation was voluntary and patients were able to withdraw at any time. Patients were asked to provide written informed consent before starting the study. Patients were identified by a study number, initials and date of birth in order to keep patients' personal and health information confidential. Ethics approval was obtained for this study from each host institution.[9]

Patients were asked to provide a HRQOL score by rating the extent to which they have experienced each item on a scale of (1) 'not at all' to (4) 'very much'. Further, patients were asked to indicate whether that particular item should be included in the final HRQOL module ('yes' or 'no').[9] In addition, patients were asked to indicate which 5–10 issues from the list they felt affected their lives most profoundly, described henceforth as the 'top ten' list. Patients were also asked to list any other experiences that were inadequately addressed by the 61-item questionnaire coupled with the EORTC QLQ-C30. Health care professionals involved in the care of patients with bone metastases were eligible for inclusion in the study. Health care professionals were asked to provide a HRQOL score by rating how relevant each item was to the patients with bone metastases ((1) 'not at all' to (4) 'very much'). The remainder of the HCP questionnaire was identical to the patients' version in its request for a 'top ten' list and supplementary items.[9]

All analyses were performed using the Statistical Analysis Software.[10] Descriptive statistics and frequency distributions were generated for the patients' demographic and disease-related characteristics. Statistical comparisons were not made between countries because of unbalanced sample sizes. The mean HRQOL scores of patients and HCPs ((1) 'not at all' to (4) 'very much') were compared using a Wilcoxon rank-sum test. A Bonferroni adjusted p-value of less than 0.001 (0.05/61) was considered statistically significant to control for multiple comparisons. Patient and HCP mean scores were grouped into six themes and the average score for each theme was calculated. The difference in patient and HCP mean scores was calculated with the HCP score as the standard (HCP value subtract patient value) because HCPs tended to score higher values than patients. For the difference in mean scores, a higher value signifies a greater difference between HCP and patient scores, and a negative value signifies that patients scored the item higher than HCPs.

The percentage of patients and HCPs who listed each item within their respective 'top ten' list was calculated. Items were ranked separately for patients and HCPs according to the frequency of inclusion in each group's 'top ten' list. The difference of patient and HCP rankings was calculated with the HCP score as the standard, and a spread of greater than 20 was considered high. Health care professionals ranked the item higher if the rank difference is negative, while patients ranked the item higher than HCPs if the rank difference is positive. An overall 'top ten' list of items for each group was generated.

3. Results

A total of 413 patients (174 males and 239 females) and 152 HCPs were interviewed. Patient median age was 64 years (30-–93 years). Breast (39%), prostate (17%) and multiple myeloma (15%) were the most common primary cancer sites. At the time of the interview, most patients had received radiation (59%), chemotherapy (54%), bisphosphonate treatment (43%) or hormonal therapy (42%). Few patients in the sample had experienced pathological fractures (7%), spinal cord compressions (5%) or hypercalcaemia (4%). The majority of the patients interviewed were English-speaking. Of the 152 HCPs interviewed, the majority were radiation oncologists (30%), medical oncologists (26%) or nurses (22%). The majority of the HCPs interviewed were from Canada. No statistically significant differences were found when patient rankings of 'top ten' items were compared to primary cancer site, duration from diagnosis of bone metastases, treatment or skeletal-related events. Table 1 lists out the demographics of patients and HCPs.

Patients and HCPs had significantly different mean scores for most of the 61 items ($p < 0.001$), but had similar mean scores for 12 items (Table 2, p values not shown). The mean scores reported by HCPs were almost always higher than those reported by patients, however patients tended to score higher than HCPs for items related to 'hope' (Table 2). The greatest difference in mean scores was observed for symptom items related to pain such as 'uncontrolled unmanageable pain not relieved by pain killers' (2.1), 'pain at night preventing sleep' (1.8), 'pain at rest (when sitting)' (1.63) and 'short-

Table 1 – Patients' (n = 413) and health care professionals' (n = 152) demographics.

Patients	n (%)	Health care professionals	n (%)
Centres/country		*Centres/country*	
PMH/Canada	132 (32%)	PMH/Canada	47 (31%)
OCC/Canada	131 (32%)	OCC/Canada	45 (30%)
TBCC/Canada	67 (16%)	Liverpool/Australia	26 (17%)
Liverpool/Australia	42 (10%)	TBCC/Canada	23 (15%)
Charité/Germany	41 (10%)	Charité/Germany	11 (7%)
Sex		*Specialty*	
Male	174 (42%)	Radiation oncologists	46 (30%)
Female	239 (58%)	Medical oncologists	40 (26%)
Age (years)		Nurses	33 (22%)
Mean ± SD	63.4 ± 11.8	Palliative care physicians	18 (12%)
Median (range)	64 (30–93)	Surgeons	7 (5%)
Primary cancer site		Social workers	5 (3%)
Breast	160 (39%)	Others	3 (2%)
Prostate	71 (17%)		
Multiple myeloma	60 (15%)		
Lung	57 (14%)		
Renal	20 (5%)		
Others	44 (11%)		
Treatment			
Radiation	242 (59%)		
Chemotherapy	231 (54%)		
Bisphosphonates	177 (43%)		
Hormonal therapy	175 (42%)		
Surgery	20 (5%)		
Skeletal-related event			
Pathological fracture	29 (7%)		
Spinal cord compression	21 (5%)		
Hypercalcaemia	16 (4%)		

PMH = Princess Margaret Hospital, Toronto, Ontario, Canada; OCC = Odette Cancer Centre, Toronto, Ontario, Canada; TBCC = Tom Baker Cancer Centre, Calgary, Alberta, Canada; Liverpool = Liverpool Hospital, Liverpool, New South Wales, Australia; and Charité = Charité Hospital (Universitätsmedizin Berlin), Berlin, Germany.

Table 2 – Mean scores reported by patients and HCPs.

Item	Difference in mean scores[*]
Uncontrolled unmanageable pain not relieved by pain killers	2.1
Pain at night preventing sleep	1.8
Confusion	1.71
Pain at rest (when sitting)	1.63
Feeling socially isolated	1.45
Short-term (or acute) severe pain	1.42
Difficulty in sitting	1.38
Difficulty in lying in bed	1.38
Limited movement due to pain	1.25
Dizziness	1.25
Pain with activity (when walking)	1.18
Fear of addiction to pain medication	1.16
Burning Sensation	1.15
Long-term (or chronic) pain	1.14
Difficulty in travelling outside the home (using public transportation, driving, sitting in car)	1.08
Worry about death	1.08
Drowsiness	1.07
Difficulty in standing up	1.04
Loss of interest in activities you normally enjoy	1.04
Financial burden due to the illness	1.04
Difficulty in lying flat	1.02
Worry about pain	1.02
Reluctance to use pain medication	1
Pain aggravation with movement or weight bearing	0.97
Tingling	0.87
Numbness	0.87
Worry about suffering	0.87
Difficulty in planning activities outside the home	0.77
Difficulty in carrying out usual daily tasks (grocery shopping, work outside the home, housework)	0.76
Difficulty in carrying out meaningful activity (including employment)	0.74
Anxiety	0.72
Ability to have sex	0.67
Worry about running out of medical treatments	0.65
Able to return to work promptly	0.62
Able to perform role functioning (including domestic and family roles)	0.6
Worry about the future	0.59
Emotional stress of diagnosis of advanced incurable cancer	0.57
Difficulty in climbing stairs	0.55
Mood changes	0.53
Frustration	0.52
Worry about ending days in a hospital or nursing home	0.52
Worry about hospitalisation	0.51
Worry about disease progression, deterioration in condition and future complications	0.51
Able to perform self-care	0.46
Difficulty in bending	0.45
Increased focus on spiritual issues	0.45
Worry about current health status	0.43
Postural problems	0.42
Worry about becoming dependent on others	0.42
Worry about becoming bed-bound	0.4
Worry about loss of mobility compromising independence	0.39
Aches and stiffness	0.25
Strengthened relationships with family and friends	0.23
Loss of interest in sex	0.11
Feel in control, positive and confident	0.03
Have a clear alert mind	0
Hope for sustained pain relief (reduce pain for as long as possible)	0
Lack of energy	–0.03
Difficulty in lifting	–0.06
Hope treatment will reduce pain as much as possible	–0.13
Hope to live as long as possible	–0.81

[*] Boxed items are not significantly different ($p > 0.001$).

term (or acute) severe pain' (1.42) (Table 2) for which scores of HCPs were higher than those of patients. Health care professionals also scored 'confusion' much higher than patients did (1.71) (Table 2).

According to 'top ten' rankings, both patients and HCPs agreed that four HRQOL items affected bone metastases patients profoundly: 'long-term (chronic) pain', 'difficulty carrying out usual daily tasks', 'able to perform self-care' and 'able to perform role functioning' (Table 3). However, the difference in ranking between the two groups was substantial with respect to the somatic and psychosocial issues (Table 4). Health care professionals valued issues related to symptoms and treatment side-effects much higher than patients as the majority of the differences in ranking of these themes were negative, with six items having a ranking discrepancy of higher than 20 points. On the other hand, patients valued psychosocial items more than HCPs as 19 of the 25 items included in the theme had positive ranking differences, with five items having a ranking difference of greater than 20 points. Health care professionals ranked psychosocial items related to pain medication much higher than patients. The 'top ten' items identified by patients and HCPs, respectively, were grouped into themes (Fig. 1). Health care professionals ranked items related to symptoms as more important to patients with bone metastases (7 of 10 items) with an emphasis on issues relating to pain (7 of 10 items). In contrast, patients focused on psychosocial items (4 of 10 items) and included three 'worry' issues within their 'top ten' list: 'worry about becoming dependent on others'; 'worry about loss of mobility compromising independence' and 'worry about disease progression, deterioration in condition and future complications', which were ranked 20th, 22nd and 16th, respectively, by HCPs (data not shown).

The 'top ten' issues for patients and HCPs in each of the three countries were compared qualitatively. Across the three countries, patients agreed that 'long-term (chronic) pain,' 'difficulty in carrying out usual daily tasks' and 'worry about loss of mobility compromising independence' were important issues. Health care professionals agreed that six issues were important enough to be included in the 'top ten' list: 'able to perform self-care', 'long-term (chronic) pain relief', 'uncontrolled, unmanageable pain relieved by pain killers', 'pain at night preventing sleep', 'limited movement due to pain' and 'pain at rest'.

4. Discussion

It is generally accepted that the patients' perspective is the gold standard for the measurement of HRQOL and as a result, they should be the primary source regarding what issues are to be included in a HRQOL assessment tool.[11]. Patients are best able to define and measure their own HRQOL because it is such a subjective experience[12]; what one patient regards as a severe problem may be considered only minimal by another patient.[13] On the other hand, HCPs tend to outline what is typical in any given situation[14] and therefore provide an external evaluation of the patients' problems and symptoms.[15] This objective perspective is also important in the development of HRQOL instruments because patients' improvements are evaluated based on the clinical parameters. Further, HCPs are responsible for the administration and incorporation of the tools into their everyday practice. Although, 82.5% of physicians felt that HRQOL research data are essential for good cancer patient care, only 26% of respondents used formal QOL questionnaires in their practice.[16] Many feel that current HRQOL instruments are too complicated, time-consuming or costly to be incorporated into clinical practice.[2,16] Bezjak and colleagues suggest that in order to maximise physician use of QOL information, we must present data in ways that are more clinically relevant.[16] Therefore, while both perspectives are important for incorporation into HRQOL assessments, they are not entirely aligned.

Our study showed that patients and HCPs value specific HRQOL concerns differently. Patients and HCPs agreed that pain and physical/role functioning are important to the HRQOL of cancer patients with bone metastases, but patients also emphasized the importance of psychosocial issues to HRQOL.

Table 3 – 'Top ten' HRQOL issues for patients and health care professionals.

Rank	Patients	%	HCP	%
1	**Long-term (or chronic) *pain***	41	**Able to perform self-care**	62
2	**Difficulty in carrying out usual daily tasks (grocery shopping, work outside the home, housework)**	40	Uncontrolled unmanageable *pain* not relieved by pain killers	61
3	*Worry* about becoming dependent on others	39	**Long-term (or chronic) *pain***	54
7	*Worry* about loss of mobility compromising independence	37	Short-term (or acute) severe *pain*	52
5	*Worry* about disease progression, deterioration in condition and future complications	32.9	*Pain* at night preventing sleep	50
6	**Able to perform self-care**	32.6	Limited movement due to *pain*	47
7	Difficulty in carrying out meaningful activity (including employment)	32	*Pain* at rest (when sitting)	45
8	**Able to perform role functioning (including domestic and family roles)**	32	*Pain* with activity (when walking)	41
9	Financial burden due to the illness	24.3	**Able to perform role functioning (including domestic and family roles)**	39
10	Hope treatment will reduce *pain* as much as possible	23.6	**Difficulty in carrying out usual daily tasks (grocery shopping, work outside the home, housework)**	36

Boldface represents items that patients and HCPs agree should be included in the 'top ten' list.

Table 4 – Comparison of the percentage of patients and health care professionals who included each item in their ‘top ten’ list and rank difference.

Items	Overall rank difference*
Reluctance to use pain medication	–33
Pain at rest (when sitting)	–31
Pain aggravation with movement or weight bearing	–26
Pain at night preventing sleep	–24
Drowsiness	–21
Confusion	–21
Short-term (or acute) severe pain	–20
Fear of addiction to pain medication	–20
Burning Sensation	–19
Pain with activity (when walking)	–18
Numbness	–18
Tingling	–16
Limited movement due to pain	–14
Difficulty in sitting	–14
Difficulty in lying in bed	–14
Uncontrolled unmanageable pain not relieved by pain killers	–12
Ability to have sex	–10
Worry about pain	–10
Difficulty in standing up	–9
Worry about death	–9
Dizziness	–6
Able to perform self-care	–5
Have a clear alert mind	–4
Worry about suffering	–4
Difficulty in lying flat	–3
Loss of interest in activities you normally enjoy	–2
Anxiety	–1
Hope for sustained pain relief (reduce pain for as long as possible)	–1
Postural problems	0
Able to perform role functioning (including domestic and family roles)	1
Long-term (or chronic) pain	2
Aches and stiffness	3
Feeling socially isolated	3
Emotional stress of diagnosis of advanced incurable cancer	3
Difficulty in bending	4
Difficulty in planning activities outside the home	5
Difficulty in carrying out meaningful activity (including employment)	5
Difficulty in lifting	5
Frustration	7
Loss of interest in sex	7
Hope treatment will reduce pain as much as possible	7
Difficulty in carrying out usual daily tasks (grocery shopping, work outside the home, housework)	8
Mood changes	8
Worry about running out of medical treatments	9
Financial burden due to the illness	9
Worry about disease progression, deterioration in condition and future complications	11
Increased focus on spiritual issues	12
Difficulty in travelling outside the home (using public transportation, driving, sitting in a car)	15
Difficulty in climbing stairs	15
Feel in control, positive and confident	15
Worry about becoming dependent on others	17
Lack of energy	18
Able to return to work promptly	18
Worry about loss of mobility compromising independence	18
Worry about the future	19
Worry about hospitalisation	19
Worry about ending days in a hospital or nursing home	21
Worry about current health status	22
Hope to live as long as possible	24
Strengthened relationships with family and friends	27
Worry about becoming bed-bound	27

* Overall rank difference was calculated by HCP’s rank subtract patient’s rank for each item.

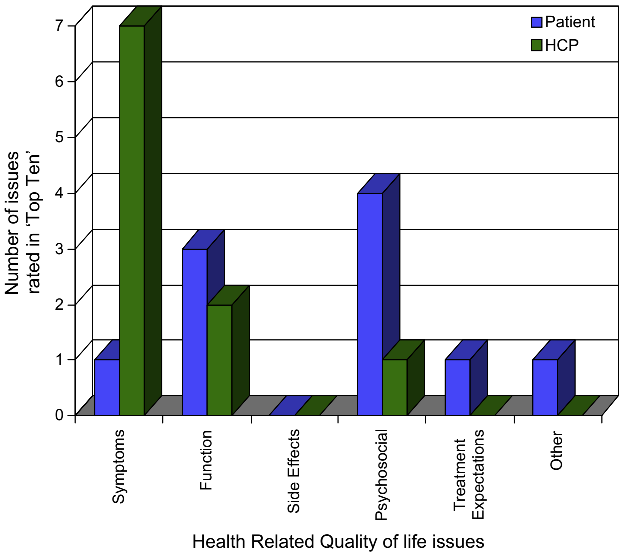

Fig. 1 – Comparison of the HRQOL items listed in patients' and health care professionals' 'top ten' lists. Items are grouped according to themes.

Our results are in accordance with several published studies that have also shown a tendency for better agreement between patient and HCP scores regarding concrete and overt symptoms, such as impaired physical functioning, vomiting and dyspnoea, and poorer agreement for subjective aspects such as emotional functioning, feelings and pain.[17] For example, Petersen and colleagues observed the poorest agreements between patients and physicians for social and emotional functioning (0.15 each) with best correlation in nausea/vomiting and constipation (0.54 and 0.60, respectively).[13]

In this study, HCPs focused on somatic issues relating to cancer pain when rating items according to perceived valuation of bone metastases patients. Unrelieved cancer pain has a negative impact on patients' HRQOL[18–24], but it is not necessarily the sole or the most significant influencer. Rustøen and colleagues found that pain characteristics only had a small impact on HRQOL, explaining just 8.6% of the variance of HRQOL scores.[7] When physical functioning and social functioning were added to the analysis the explained variance increased to 28.4%, however depression seemed to have the most significant impact with an increase of 14–42.4% of the explained variance.[7] Further, the Initiative on Methods, Measurement and Pain Assessment in Clinical Trials (IMMPACT) group recommends that six core outcome domains are pertinent to outcome measurement of chronic pain including physical, emotional and social functions.[25] Thus, chronic pain is a multidimensional construct that impacts patients' lives in a variety of ways and the relevance of each domain may vary according to the stage of illness, treatment, age and cultural background. Health care professionals need to be careful that they are not analysing such a construct from only the physical dimension. In this study, among others, patients have made it clear that psychosocial issues are important influencers of their perceived HRQOL.

A possible explanation for the observed discordance between patients and HCPs, valuation of items impacting HRQOL lies in the focus of relief of cancer pain in the bone metastases population. Cancer pain is a significant problem in this population[26] and many of the HCPs evaluated in this study are involved with its treatment. Specialisation in the treatment of cancer pain may explain the clear emphasis by HCPs on issues related to pain. Further, physicians may also feel that they are unable to change many of the causes of psychosocial disturbances and therefore opt to concern themselves with symptoms that they can help such as pain. Unfortunately, this study did not have the adequate sources for evaluation of differences in valuation between HCPs who treat the physical symptoms of cancer pain (oncologists and surgeons) and those who possibly treat the patients from a broader perspective (spiritual and social workers). It is recommended that differences in evaluation between HCPs be investigated in future studies to determine if the area of specialty relates to perceptions of items influencing patients' HRQOL.

Another explanation may stem from the scope and scale of patient-physician communication. In a study by Detmar and colleagues, almost all patients expressed a willingness to discuss the physical and emotional aspects of their disease.[15] However, a quarter of the patients were only willing to discuss emotional functioning at the initiative of their physician. An even greater reluctance was observed concerning the issues of social functioning and family life, with 28–36% of patients waiting for the doctor to first raise the topic and another 20% choosing not to hold a discussion on these issues at all. This suggests that patients may be uncertain about which issues are appropriate to be discussed with their physician.[15] Physicians themselves felt that discussion of the physical aspect of their patient's health was primarily their responsibility, while a number of physicians indicated that the discussion of psychosocial health problems should be shared with other health care providers.[15] In the case of emotional and social functioning, all physicians indicated that they generally defer the initiation of the topics to their patients.[15] Consequentially, this confusion regarding the appropriate allocation of responsibility may hinder the discussion of psychosocial issues, which can impede appropriate symptom identification and increase the risk of inadequate treatment[27] as physicians tend to overlook problems and symptoms that are not obvious or mentioned explicitly by the patient.[13]

The sample for this study was large and extended across multiple centres and countries, providing adequate power for statistical analysis of differences in patient and HCP valuation of items. Almost all items were deemed relevant to patients, which attests the success of the initial item-generation phase. A diverse demographic of cancer patients with bone metastases was sampled, with patients undergoing a variety of treatment disciplines at the time of interviews. This is consistent with the current multidisciplinary setting in most hospitals worldwide and provides support for the generalisability of the results to the disease-specific patient population surveyed. In sum, the data appear robust and are a fair representation of the populations surveyed.

However, our study is not without limitations. The data collected were primarily quantitative and may not represent the scope of the HRQOL issues identified. We attempted to compensate for this limitation by giving patients and HCPs the opportunity to add items other than the 61 specified. Although we surveyed a large number of patients and HCPs, the surveys were conducted on a voluntary basis and therefore misconceptions due to the effects of sampling error must be considered. The greatest percentage of HCP responses were from oncologists, which may have skewed HCP results to items valued by this particular group, namely somatic issues. Further, the majority of the patients were English-speaking and therefore results may not be generalisable to other populations. The majority of the participants interviewed were from Canada with smaller samples from Germany and Australia and therefore comparisons between countries could not be evaluated quantitatively. We invite others to replicate this analysis with a broader population to confirm our study's results.

In conclusion, this study demonstrates that patients and HCPs have different valuation of items influencing HRQOL for patients with bone metastases. It is important that HCPs recognise these differences in their clinical practice to better improve their understanding of the spectrum of symptoms important to the patient. Although it may not be possible to alleviate patients' worries and concerns in a population where the disease is essentially incurable, a simple discussion of these issues is very important to patients. However, it appears that patients' concerns regarding psychosocial matters are not raised as often as they should be, in part, due to the reticence of both patients and physicians. If we are able to understand the patients' perspective of their illness, we can develop management strategies appropriate to their individual needs. Ongoing developments of HRQOL instruments should aim to identify and include issues that affect patients' HRQOL experience most strongly whilst providing an objective assessment tool for HCPs to adopt into their everyday practice. Without the embracement and employment of the HRQOL tool by the HCPs everyday its development is of little use. Through this concept of objective assessment and the facilitation of open communication we can hope to improve the chances that physicians and patients will use the HRQOL information generated effectively.

The EORTC QLQ-BM22 provides a comprehensive evaluation of the symptoms of bone metastases and the benefits and possible side-effects of interventions employed. This instrument is of value for the measurement of HRQOL in international clinical trials as well as for the longitudinal follow-up of patients with bone metastases. Further, the adoption of this tool into everyday clinical practice provides HCPs the opportunity to gather more information about their patients, provide better consultations and in turn, better alleviate the distinct issues associated with bone metastases for their patients.

Conflict of interest statement

None declared.

Acknowledgements

We thank all the patients, health care professionals and research assistants who assisted in the administration of this study. This project was generously supported by grants from the National Cancer Institute of Canada; Deutsche Krebshilfe, Bonn, Germany; and by an unrestricted educational grant from Novartis Oncology. We thank Amanda Hird, Janet Nguyen and Stacy Lue for their assistance in this study.

REFERENCES

1. Ferrans CE. Development of a quality of life index for patients with cancer. *Oncol Nurs Forum* 1990;**17**:15–9.
2. Movsas B. Quality of life in oncology trials: a clinical guide. *Radiat Oncol* 2003;**13**:235–47.
3. Chochinov HM. Depression in cancer patients. *Lancet Oncol* 2001;**2**:499–505.
4. Degner L, Sloan J. Symptom distress in newly diagnosed ambulatory cancer patients and as a predictor of survival in lung cancer. *J Pain Symptom Manage* 1995;**10**:1–8.
5. Sloan JA, Loprinzi CL, Kuross SA, et al. Randomized comparison of four tools measuring overall quality of life in patients with advanced cancer. *J Clin Oncol* 1998;**16**:3662–73.
6. Bezjak A, Ng P, Taylor KM, MacDonald K, Depetrillo AD. A preliminary survey of oncologists' perceptions of quality of life information. *Psycho-oncology* 1997;**6**:107–13.
7. Rustøen T, Moum T, Padilla G, Paul S, Miaskowski C. Predictors of quality of life in oncology outpatients with pain from bone metastasis. *J Pain Symptom Manage* 2005;**30**:234–42.
8. Barton MB, Dawson R, Jacob S, et al. Palliative radiotherapy of bone metastases: an evaluation of outcome measures. *J Evaluat Clin Pract* 2001;**7**:47–64.
9. Chow E, Hird A, Velikova G, et al. The European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire for patients with bone metastases: the EORTC QLQ-BM22. *Eur J Cancer* 2009;**45**:1146–52.
10. SAS Institute. SAS/STAT user's guide, version 9. Cary, NC: SAS Institute Inc.
11. Costantini M, Mencaglia E, Giulio PD, et al. Cancer patient as 'experts' in defining quality of life domains. A multicentre survey by the Italian Group for the Evaluation of Outcomes in Oncology (IGEO). *Qual Life Res* 2000;**9**:151–9.
12. Higginson IJ. Can professionals improve their assessments? *J Pain Symptom Manage* 1998;**15**:149–50.
13. Petersen MA, Larsen H, Pedersen L, Sonne N, Groenvold M. Assessing health-related quality of life in palliative care: comparing patient and physician assessments. *Eur J Cancer* 2006;**42**:1159–66.
14. Anon. Quality of life from a patient's perspective: can we believe the patient? *Curr Probl Cancer* 2005;**29**:326–31.
15. Detmar SB, Aaronson NK, et al. How are you feeling? Who wants to know? Patients' and oncologists' preferences for discussing health-related quality-of-life issues. *J Clin Oncol* 2000;**18**:3295–301.
16. Bezjak A, Ng P, Skeel R, DePetrillo AD, Comis R, Taylor KM. Predicting oncologists' use of Quality-of-Life (QOL) data: results of a survey of Eastern Co-operative Group (ECOG) physicians. *Qual Life Res* 2001;**10**:1–13.
17. McPherson CJ, Addington-Hall JM. Judging the quality of care art the end of life: can proxies provide reliable information? *Soc Sci Med* 2003;**56**:95–109.
18. Ferrell B, Grant M, Padilla G, Vermuri S, Rhiner M. The experience of pain and perceptions of quality of life: validation of a conceptual model. *Hosp J* 1991;**7**:9–24.
19. Miaskowski C, Dibble SL. The problem of pain in outpatients with breast cancer. *Oncol Nurs Forum* 1995;**22**:791–7.
20. Rummans TA, Frost M, Suman VJ, et al. Quality of life and pain in patients with recurrent breast and gynecologic cancer. *Psychosomatics* 1998;**39**:437–45.

21. Strang P, Qvarner H. Cancer-related pain and its influence on quality of life. *Anticancer Res* 1990;**10**:109–12.
22. Sandblom G, Carlsson P, Sigsjo P, Varenhorst E. Pain and health-related quality of life in a geographically defined population of men with prostate cancer. *Br J Cancer* 2001;**85**:497–503.
23. Burrows M, Dibble SL, Miaskowski C. Differences in outcomes among patients experiencing different types of cancer-related pain. *Oncol Nurs Forum* 1998;**25**:735–41.
24. Esnaola NF, Cantor SB, Johnson ML, et al. Pain and quality of life after treatment in patients with locally recurrent rectal cancer. *J Clin Oncol* 2002;**20**:4361–7.
25. Dworkin RH, Turk DC, Farrar JT, et al. Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. *Pain* 2005;**113**:9–19.
26. Pain Palliation of Bone Metastases – Overview. InSightec.com. InSightec Image Guided Treatment Ltd. <http://www.insightec.com/135-en-r10/BoneMetastases.aspx>; 2005 [01.04.05].
27. Brunelli C, Constantini M, Di Giulio P, et al. Quality-of-life evaluation: when do terminal cancer patients and health-care providers agree? *J Pain Symptom Manage* 1998;**15**:151–8.