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1.0 Introduction

Advances in cancer treatment are significantly improving patient survival, in many cases transforming cancers with a poor prognosis into manageable chronic diseases.¹ Worldwide, there are more than 32 million individuals living with cancer.² Even patients with advanced disease can have extended survival with newer treatments.^{3,4} Despite therapeutic advances, patients surviving over the long-term face a host of challenges, such as symptom burden, treatment-related side effects, diminished quality of life (QoL), comorbid conditions, and economic losses.^{1,5-11} Substantial burdens may also be placed on patients' informal caregivers and families.^{10,12-18}

Such issues have sparked interest in the long-term impact of cancer on patients.^{1,19} It has been recommended that studies examine not only how long patients live, but also how well they survive.⁷ Although some recently introduced therapies have the potential to substantially prolong life after treatment discontinuation even in advanced solid tumors,^{3,4,20} information related to the quality of this prolonged survival period is lacking. Traditional trial endpoints (e.g., median overall survival [OS], median progression-free survival, objective response rate, and adverse events), which are usually assessed only for a few months from last treatment, tell us little about the quality of long-term survival. The nature of patient populations (eg limited life expectancy for many tumor types) and characteristics of trial designs tend not to fully capture the survivorship experience since they are typically only employed during the treatment phase

and may not sufficiently probe all pertinent areas of concern to patients such as life satisfaction, identity, self-esteem, confidence with appearance, and social support.

To address such data gaps, we propose a new concept termed “quality of survival” (QoS), the scope of which extends beyond traditional metrics and takes into account both the extension of life and the quality of that prolonged survival across the entire cancer continuum. We developed a QoS concept map first via a targeted landscape literature review and later investigated its potential utility through interviews with patients, clinicians, and payers. This framework was discussed in the context of two relevant tumor types, metastatic non-small cell lung cancer (NSCLC) and metastatic melanoma, which historically have had 5-year survival rates of only 2%²¹ and 15% to 20%,²² respectively.

2.0 Methods

2.1 Literature-based landscape research

An exploratory literature-based landscape review investigated cancer survival or survivorship and identified any related research, data, and gaps in the field. Peer reviewed and non-peer-reviewed literature was identified. An electronic database search collected published articles and an additional web-based search retrieved treatment guidelines, disease forums, and patient advocacy association web sites (Table 1). Due to the exploratory nature of the research, an iterative approach was taken rather than a formal search strategy which is required for a structured literature review. English language material was retrieved and reviewed in November 2013.

Outputs were used to support the development of a preliminary QoS concept map, which was ratified and adapted further - based on physician and payer insights. We did not test the QoS map directly with patients because the goal was to learn about their experiences and

expectations, without presenting preformed ideas. The usefulness and meaningfulness of the QoS map in practice was tested with physicians and payers.

2.2 Patient Interviews

Thirty-five patients (20 with metastatic NSCLC from the United States and 15 with metastatic melanoma from Canada; see eTable 1 in the Supplement) were interviewed. This number was considered sufficient to achieve saturation in each indication.²³ Patients were recruited through partner agencies and face-to-face or telephone interviews were conducted. Patients were ≥ 18 years of age, had a diagnosis of metastatic NSCLC or metastatic melanoma, and were currently receiving treatment. Semi-structured 1-hour interviews (see patient interview guides in the Supplement) explored the following areas: (1) symptoms, disease/treatment communication, and education; (2) patient expectations about treatment goals and involvement in decision making; and (3) impact of all of the above on patients, families, and friends. While most interviews were qualitative, with a mixture of open-ended questions and direct probes, quantitative survey questions were included.

2.3 Clinician Interviews

Forty medical and radiation oncologists specializing in metastatic NSCLC or metastatic melanoma in both the community and academic sectors from the United States, the United Kingdom, France, and Germany (5 metastatic NSCLC and 5 metastatic melanoma specialists per country; see eTable 2 in the supplement) were interviewed. Clinicians were recruited via partner market research agencies in each country. This number was considered robust for qualitative research.²³ Clinicians were required to see at least two patients with metastatic NSCLC or metastatic melanoma per week (8–10 patients per month). Academic clinicians were required to spend at least 50% of their time treating patients.

Clinician interviews consisted of one-hour, semi-structured, telephone conversations based on an interview guide with open-ended, unbiased questions (see clinician interview guide in the Supplement). Interviews were coded according to core themes using Atlas.ti software version 7 (Berlin: ATLAS.ti Scientific Software Development GmbH; 2013). Explored themes included: (1) disease presentation in metastatic NSCLC and metastatic melanoma; (2) disease communication, education, and support; (3) care plan drivers and decision-making; (4) treatment drivers and decision-making; (5) long-term survivorship; and (6) QoS concept map and concept statements. The term “survival” was used during the interviews and in the concept map as a generic term that indicated the patient is alive.

2.4 Payer Interviews

Semi-structured telephone interviews (see payer interview guide in the Supplement) were conducted with representatives from 7 payers in the United States (n=2), United Kingdom (n=2), Germany (n=2), and France (n=1), who are involved in making market access or reimbursement decisions for oncology agents, specifically those for metastatic NSCLC and metastatic melanoma (see eTable 3 in the Supplement). Payers were recruited via partner market research agencies in each country. A range of payer types (national-level/health technology assessment [HTA] payers or health economists advising HTA bodies, and local/regional payer decision-makers) were included to capture different opinions. Payers’ reactions to the draft QoS concept map and concept statements were analyzed. Explored themes included: (1) cost drivers of cancer care; (2) definitions of time frame/long-term survivorship; (3) assessment of time frame/long-term survivorship; (4) impact of time frame/long-term survivorship on decision making; (5) value of long-term survival in relation to treatments; and (6) QoS concept map and concept statements.

3.0 Results

3.1 Literature-based landscape research

The literature-based landscape review showed a growing awareness of the long-term impact of cancer on patients and the importance of assessing long-term experience.²⁴⁻²⁶ Recently, survivorship initiatives and care programs focusing on long-term needs of patients have been initiated in the United States^{1,19,27} and Europe.^{28,29} For example, the National Cancer Survivorship Initiative (NCSI) was launched in 2010 in the United Kingdom to assist patients living with and beyond cancer.²⁸ Additionally, patient/caregiver forums, patient surveys, and blogs provide evidence for the multifaceted nature of expectations of patients with cancer and their families for long-term survival.

Although articles highlight the current interest in quality of extended survival, the focus is largely on QoL tools.³⁰⁻³² Several patient-reported outcome (PRO) tools are commonly used in cancer to measure QoL or other burdens (e.g., symptoms), and new ones are being developed (e.g., financial distress tool³³), but no QoS PRO was identified due to the multiple domains encompassed by the concept. While origins of the term QoS can be traced back to the 1980s,^{34,35} it described QoL and was used infrequently in subsequent years.

Based on the landscape research, a preliminary QoS concept framework was developed consisting of five interconnected dimensions: QoL, survival/survivorship, managing the side effects (during and post treatment), managing the cost of surviving, and communication and education (Figure 1).

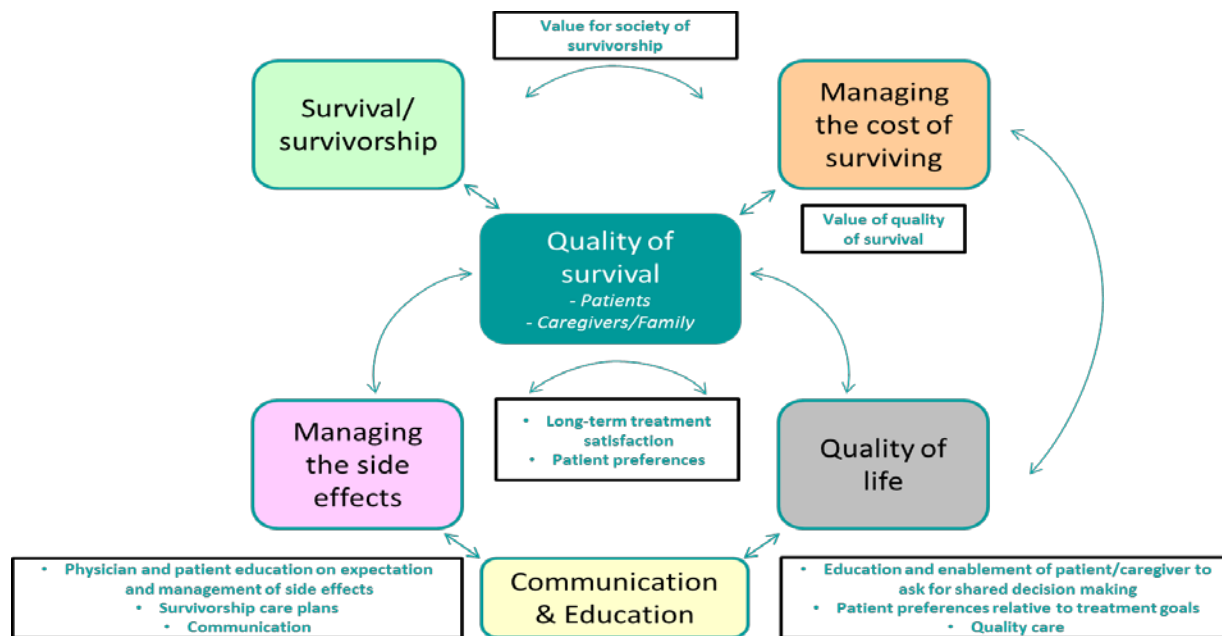
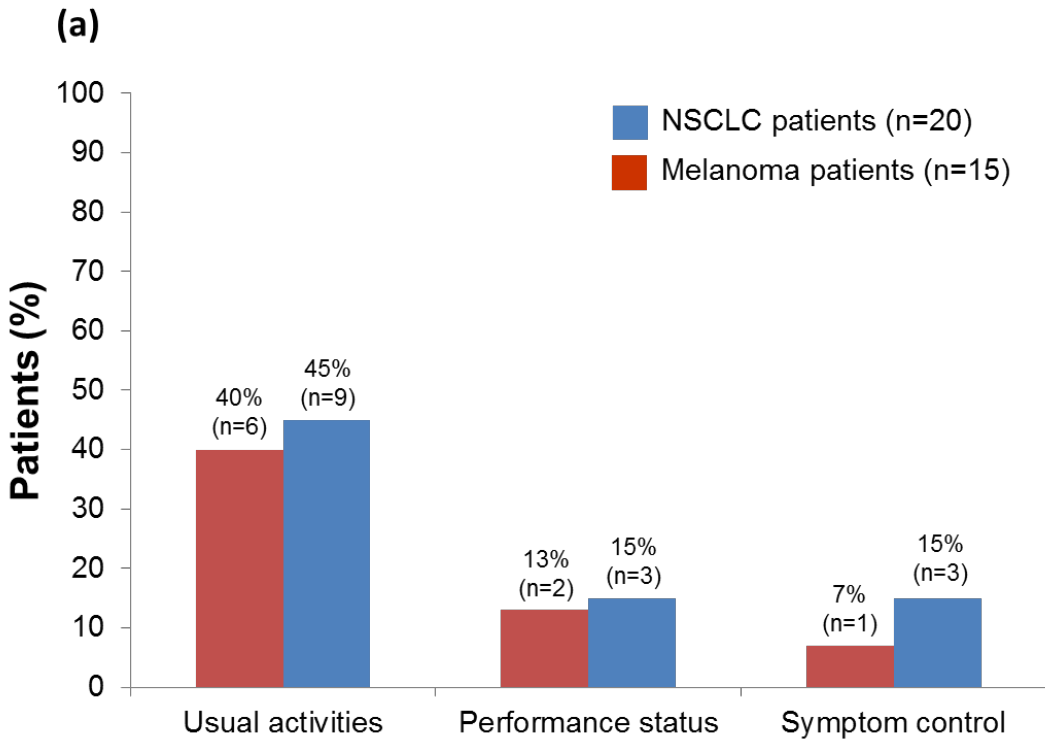


Figure 1. Preliminary QoS concept map developed based on literature research.

3.2 Patient interviews

Among the 35 patients, extended survival via reducing/controlling tumor size, spread, and progression was reported as a primary treatment goal at diagnosis (NSCLC: 10/20 [50%]; melanoma: 6/15 [40%]). In aiming to live longer, NSCLC patients (8/20 [40%]) hope to achieve a return to/preservation of “normality” with regard to functioning and activities of daily living (i.e., maintenance of QoL). The primary goal of treatment for melanoma patients was less about a return to/preservation of normality but to be cured (7/15 [47%]), implying that melanoma patients do not experience impacts to the same extent as NSCLC patients. The most reported factor in defining a “good day” was being able to participate in usual activities (Figure 2A), while that in defining a “bad day” was poor symptom control (Figure 2B).



(b)

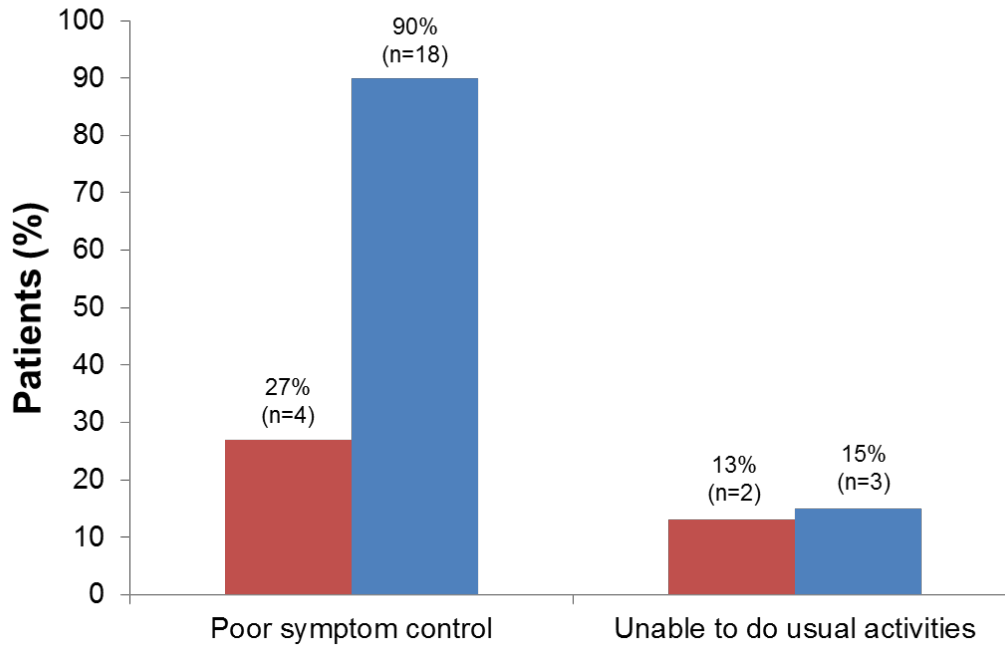


Figure 2. (A) Patient views on characteristics of “good day” with cancer. (B) Patient views on characteristics of “bad day” with cancer.

Several impacts were reported by NSCLC (Figure 3A) and melanoma (Figure 3B) patients, which also affected caregivers and family. The most common impacts in NSCLC patients were physical, with fatigue/tiredness being the most frequent. NSCLC patients reported that the symptoms/side effects (5/20 [25%]) were the most bothersome aspect of lung cancer on a typical day. All melanoma patients (15/15 [100%]) described impacts on their lives, with the most common being emotional (13/15 [87%]), physical (12/15 [80%]), and work-related (12/15 [80%]). The most commonly reported physical impacts in melanoma patients were increased tiredness/fatigue (7/15 [47%]) and limitations in ability to exercise (5/15 [33%]). Financial impact was also reported by NSCLC and metastatic melanoma patients (Figures 3A and 3B).

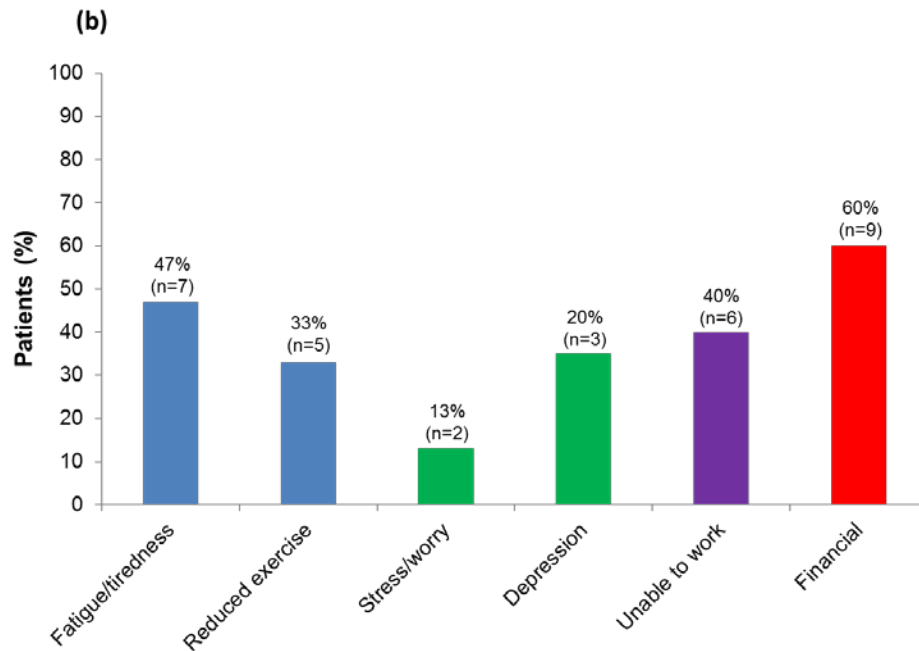
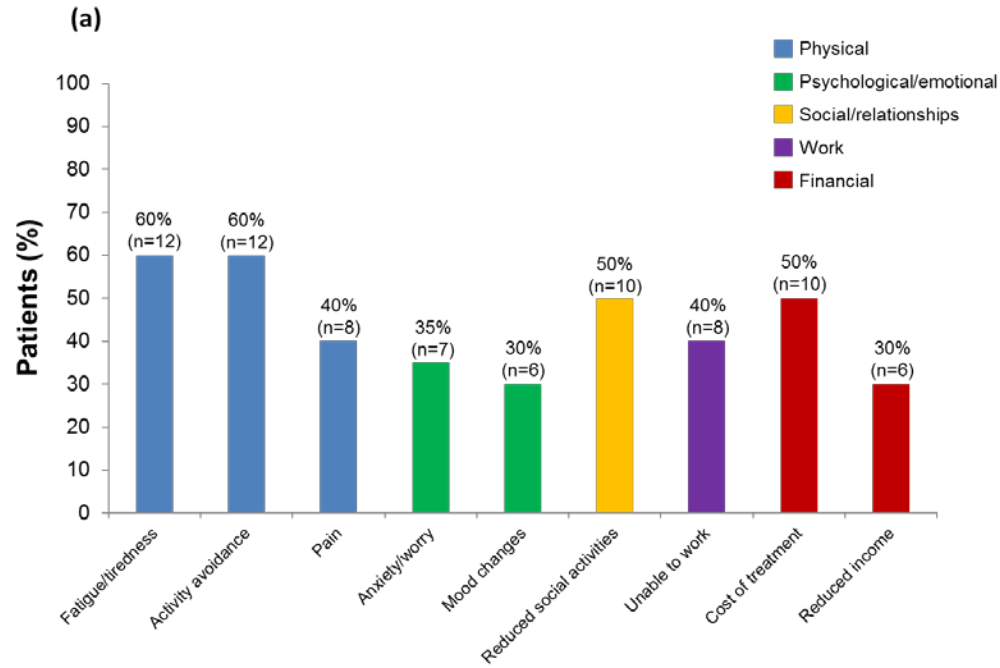


Figure 3. (A) Impacts throughout the disease/treatment continuum on metastatic NSCLC patients (n=20); (B) Impacts throughout the disease/treatment continuum on metastatic melanoma patients (n=15).

Half of NSCLC patients (50% [10/20]) largely had realistic expectations that their disease/treatment journey would be long and they anticipated multiple and long-term treatment cycles to manage, but not “cure”, their disease. Some NSCLC patients (20% [4/20]), however, did expect to recover and used terms such as “remission”, “be cancer free”, and “beat the cancer”.

3.3 Clinician interviews

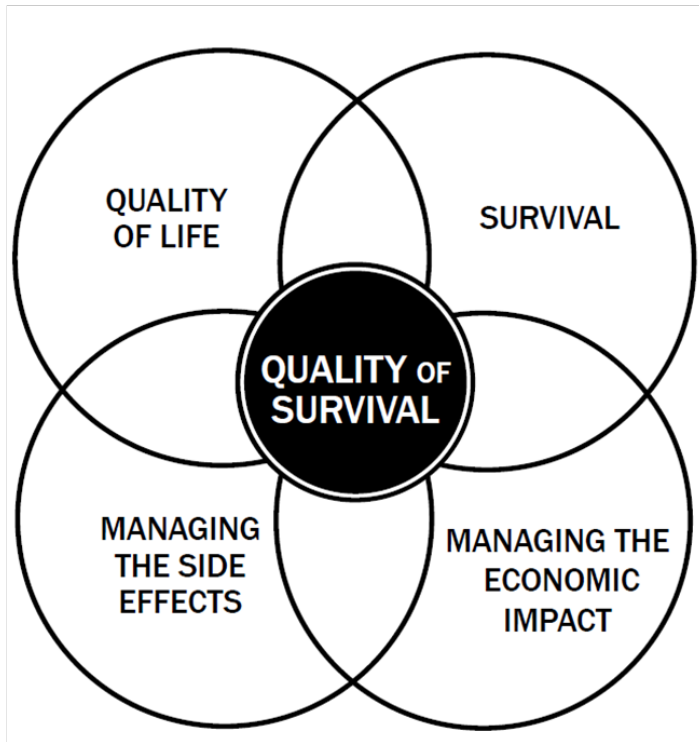
Among the 40 clinicians, controlling symptoms (n=23 [58%]) and improving QoL (n=12 [30%]) were reported as the key goals of treatment. Upon a patient embarking on treatment, survival is the primary goal for clinicians (n=15 [38%]). However, QoL becomes more important than survival as treatment toxicity and side effects take effect. Side effects (n=14 [35%]) and economic impacts (n=5 [13%]) were also considered important factors in decision making.

Most clinicians (n=23 [58%]) defined QoS as a combination of good QoL and survival. Factors felt to define QoS were QoL (n=13 [33%]), performance/functional status (n=10 [25%]), patient independence (n=6 [15%]), symptom experience (level of impact, control and relief; n=5 [13%]), and treatment toxicity (n=5 [13%]). Seventeen clinicians (43%) believed that QoS is not a static concept, with the importance of each dimension changing across the cancer continuum. Ten clinicians (25%) believed QoS was an important term because it refers to the balance between treatment toxicity and treatment benefit. Nine clinicians (23%) thought QoL and QoS had the same connotations. Clinicians felt awareness of QoS within the healthcare sector could be improved through education (n=4 [10%]) and promotion (n=3 [8%]). However, the QoS concept needed refining before awareness could be improved. In their view, a QoS measure should be clinically meaningful, applied within a multidisciplinary approach, broadly measured across diseases, used as a clinical trial endpoint, and related to specific time frames.

The preliminary QoS concept framework (Figure 1) developed based on the literature research was shared with the clinicians during interviews. Clinicians were positive about this map and few suggested changes. They generally felt that the terminology and layout of the map were appropriate; 14 (35%) were happy with the terminology, reporting it as “simple,” “straightforward,” “appropriate,” and “understandable.” Two clinicians (5%) disliked the term “cost”, reporting it sounded negative. One clinician (3%) suggested changing the wording to “economic burden”. Three clinicians (8%) felt that the term QoS needed to be defined.

Clinicians thought the map was potentially relevant to a range of stakeholders, especially patients (n=16 [40%]) and healthcare professionals (n=11 [28%]). However, the preliminary model has been amended based on clinician input. Clinicians proposed that the map have four dimensions: QoL, survival/survivorship, managing the treatment side effects, and managing the economic impact (Figure 4A). Communication and education, originally the fifth dimension, was removed since the QoS concept was thought in itself to be a communication tool. The four dimensions were viewed as interconnected (Figure 4A) and varied in importance along the care continuum (Figure 4B). At diagnosis, QoL and survival were perceived by clinicians as the primary concerns for patients. QoL and survival had continued salience during treatment, but managing side effects and patient preferences were priorities. During the post-treatment period, the economic impact and late effects of cancer appeared increasingly important, together with the societal value of a longer and re-normalization of life.

(a)



(b)

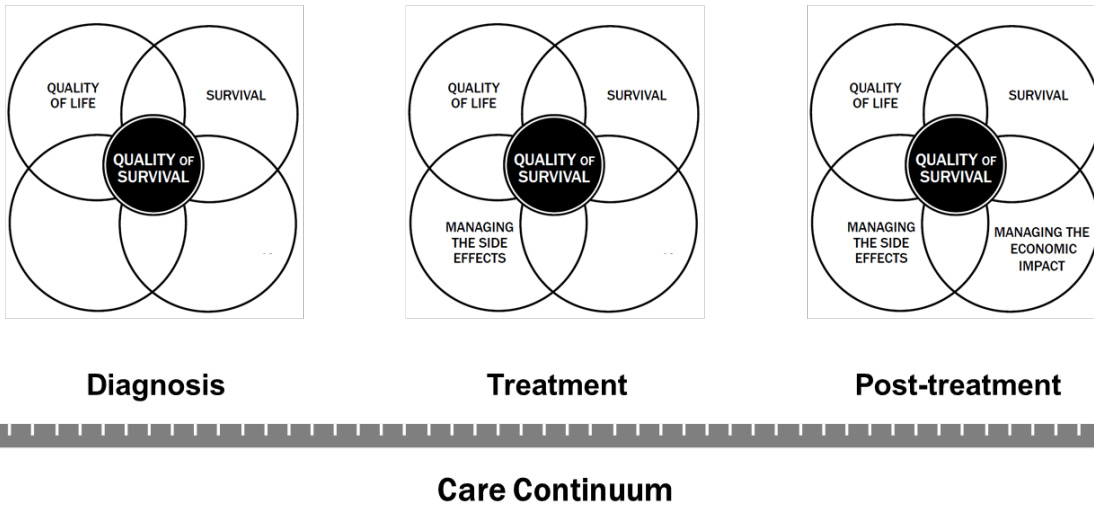


Figure 4. (A) Clinician-endorsed QoS concept map. (B) QoS concept map dimensions along the care continuum.

3.4 Payer interviews

Among the 7 payers, there was no consensus on what defines QoL; their perceptions of QoL specifically included cure/remission, performance status, productivity, side effects, adverse event impact, and inconvenience. Most payers (n=4 [57%]) agreed that a combination of existing, well-accepted QoL instruments should be used to measure long-term QoL. Payers felt survival is still the most important factor in decision-making. According to a US payer, for example, an increase in survival beyond weeks/months is increasingly being required to demonstrate value (e.g., in metastatic lung cancer, improved survival by a third of patients receiving standard of care; in metastatic melanoma, a long-term remission rate of 40%). However, a shift in mind-set to survival with improved QoL is occurring. The terminology “living with cancer” held value as it demonstrated that cure cannot be guaranteed, but that the aim is to extend life while improving QoL. Side effects tended to be considered following efficacy and survival considerations in France, Germany, and the United States (n=3 [43%]). Cost was considered important for payer decision-making in the United States and United Kingdom; however, it was secondary to survival (n=3 [43%]).

Payers were not aware of the term QoS and generally identified survival and QoL as potential constituents of QoS. Some did not make a distinction between QoL and QoS (n=3 [43%]), and most felt there is overlap between QoS and QoL (n=5 [71%]). Payers viewed the map as a general template in need of tailoring according to the context in which it would be used. Payers felt the concept map could be used alongside robust data, mainly within the clinical community. Some payers noted that although the concept would not be the primary criteria for decision-making, it could aid communication between payer groups, and may help communicate different QoS aspects relevant to the patient.

4.0 Discussion

The literature-based landscape research and patient, clinician, and payer interviews supported the development of a QoS concept map. As the literature search was exploratory in nature, the authors acknowledge that some gaps in the evidence may exist. However, recently published literature is consistent with our landscape research, describing the challenges faced by cancer patients who survive over the long-term and the need to address such challenges.³⁶⁻³⁹ Although the literature review highlights increasing interest in the quality of extended survival in cancer, the focus remains on QoL in the traditional sense. Consequently, many areas of concern to patients are not measured, including physical discomfort, emotional strain, economic burden, day-to-day function, and impacts on caregivers and families. In the interviews, patients reported a host of impacts that affect QoS. The QoS map could provide a framework to monitor patient experience throughout the cancer continuum and help patients frame what treatment attribute is most important to them at any point in the continuum. For instance, patients' primary goals of treatment at diagnosis were extended survival and return to normality, which are reflected in the QoS concept. Additionally, clinicians viewed the QoS concept as relevant to treatment decisions, and payers felt the map could help communicate different QoS aspects relevant to the patient. Based on these findings, a patient-centric QoS map emerged comprised of four interconnected dimensions ([1] QoL, [2] survival, [3] treatment-related side effects, and [4] economic impact).

QoS evolves from the traditional concept of QoL, but differentiating the two is not intuitive. Because of the potential for confusion between QoL and QoS, there is the need for further educating patients, physicians, and payers on the differences between these metrics. QoS would not replace QoL, but would incorporate factors that are important to patients. Existing health economics metrics, such as Quality-Adjusted Time Without Symptoms and Toxicity,⁴⁰ which assesses trade-offs between improved survival and treatment toxicity, and Quality

Adjusted Life Year,⁴¹ which combines survival duration with QoL, do not entirely capture QoS dimensions.

While different patient populations may drive differences in QoS measurement, the core concept would remain the same. The QoS concept map may also be used to generate assessment tools to help assess survivorship care plans, which currently vary greatly.^{19,42} It may also facilitate patient-physician communication. Traditional outcome measures in clinical trials may not capture all the meaningful long-term benefits (or comparative harms) of anti-cancer agents that are experienced by patients, especially in an era of targeted therapeutics and immune-oncology agents. While QoS focuses on patient outcomes, it is likely to be relevant to other stakeholders (e.g., clinicians, caregivers, family, and society) as a framework for considering the value of long-term, disease-free survival and has the potential for being applied as a new “value metric,” evaluating whether a treatment’s benefits are justified.⁴³ The use of a more patient-centric metric of long-term survival could facilitate shared decision making between patients and physicians, potentially leading to increased value-concordant treatment decisions and improving patient satisfaction with their long-term care.

Although the QoS concept map has been supported by our study, additional research is required to further describe each domain. Survival, for example, can be delineated in various ways (e.g., time alive since diagnosis or therapy completion, time without disease progression, or time in complete remission). Clinicians in our study spoke about survival, but did not specify how it should be measured. The distinction between “survival” and “survivorship” is also not clear, with an on-going debate over whether “survivor” is an appropriate label throughout the cancer continuum.^{44,45} Patients and clinicians may also differ on this point. The definition of long-term survival also varies according to tumor type and prognosis.

While QoS can be applied to all tumor types, the concept framework may be most useful for those cancers with more favorable prognoses, allowing QoS to be assessed across the cancer continuum. This map is flexible enough to be used for patients who continue on or have ended treatment. With the emergence of more effective treatments, the QoS concept may become useful in tumors previously with limited survival potential (e.g., advanced melanoma and NSCLC). The QoS concept should be validated in various tumor types.

Educational resources may be required to elucidate QoS dimensions most relevant to patients at each step of the cancer care continuum. Clinician did not have recommendations about QoS-specific PRO measures. Formulating a standardized QoS metric is a challenging next step. As noted in the landscape review, many of the QoS concepts are multidimensional and could be measured by incorporating some existing PRO measures and survival endpoints, rather than developing entirely new instruments. Finally, it was agreed that the concept map should be underpinned with both trial data and real-world data.

The need for an accepted integrated QoS framework has been documented here. The QoS map could be easily applied across tumor types and treatment approaches. While we found similar interest and opinions from interviews of a small group of patients, clinicians, and payers, findings should be confirmed with larger and diverse populations, with the ultimate goal of application in real-life practice.

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