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Title: Patient-centered care: making cancer treatment centres accountable

Running title: Measuring patient-centered cancer care

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Abstract

Patient-centered care is argued to be an essential component in the delivery of quality health and cancer care. This manuscript discusses the need to generate credible data which indicates the quality of patient-centered care provided by cancer treatment centres. Patient-centered care covers six domains including physical comfort; emotional support; respect for patients' preferences and values; integration and co-ordination; involvement of family and friends; and the provision of information, communication and education to enable patients to understand and make informed decisions about their care. First, we identify priority areas within each domain. Next, we propose three questions that should be asked of every patient across the six domains of patient-centered care. The first question explores whether patients were specifically *asked* by a health provider at the cancer treatment centre about their concerns, values and preferences. Research indicates that it cannot be assumed that clinicians are aware of patient's needs or preferences in these six areas. Second, if the answer from the patient suggests that they would like assistance, then it would be expected that this would be offered. Thirdly, if the patient indicates that they would like such assistance and it is provided, then it might be expected that the patient would report that the provided assistance did relieve their suffering, or the assistance provided was consistent with their preferences, needs and values. Regular measurement and reporting of these aspects of patient-centered cancer care has the potential to identify deficits and inequities in care delivery, allow for comparisons across treatment centres, and stimulate an improvement in the patient-centered care provided to cancer patients.

Introduction

Patient-centered cancer care is an essential component of quality cancer care.[1] While a number of similar definitions of patient-centered care have been proposed [2], Gerteis'[3] comprehensive definition has been endorsed by the Institute of Medicine [1], and is the most frequently used. Patient-centered care is: a) responsive to consumer needs, values and preferences; b) integrated and co-ordinated; c) relieves physical discomfort; d) provides emotional support; e) allows for the involvement of family and friends; and f) supports the provision of information, communication and education to enable patients to understand and make informed decisions about their care.

Why should we routinely assess patient-centered care?

Monitoring the functioning of oncology services via the routine measurement of quality indicators is firmly embedded within quality improvement approaches.[4] Quality indicators seek to measure aspects of health care delivery, commonly clinical effectiveness, efficiency and safety. Common indicators include mortality, waiting time for cancer surgery, receipt of evidence-based treatments, and adverse events. Given the emphasis on patient-centered care as a quality dimension in recent years, there is a groundswell support for the need to regularly measure the delivery of patient-centered care.[5] As patient-centered care is a multidimensional construct, each of the six dimensions of patient-centered care should be pursued to facilitate improvements in quality of care.[1]

Patient-centered care is a personal patient experience and is best measured by patient self-report.[6] While patient-reported outcome measures such as health related quality of life[7] and unmet supportive care needs[8] surveys have been used to indicate quality of care, they have limitations. Outcomes such as quality of life are not solely attributable to the quality of patient-centered care with factors such as the quality of technical care and disease variables contributing to the outcome. Furthermore, quality of life surveys do not provide specific feedback about the changes that an individual treatment centre can initiate to improve this outcome. Unmet needs surveys shift the focus towards quality of cancer care delivery, and can provide more nuanced feedback for quality improvement activities. However, unmet needs measures may introduce too much variability as they measure the gap between patients' experience and their expectations, and each patient has a different level of expectation. Consequently, there is a need to reduce subjectivity by measuring patients' experiences of the care pathway against explicit and quantifiable criteria that represent quality practice.[9]

What should we measure?

Priority quality indicators across each of the six domains

Given the breadth of each of the six dimensions of patient centered care, if we wish to evaluate care delivery with limited time and resources, and using a survey of acceptable length to patients, then it may be necessary to prioritise patient-centered quality indicators. [10,11] To ensure we ask the most important questions, the application of a set of principles may help to guide healthcare priority setting. We propose four principles that can be consulted to guide the identification of priority issues of patient-centered care within each domain.

1. *The issue must be prevalent.* Current and future prevalence of a health care problem is often a key principle applied by the World Health Organisation to assist with priority setting.[12] If we wish to achieve good return on healthcare investment, targeting those health service issues that are most prevalent is an important first step.
2. *Failure to deliver the care will result in significant patient burden.*[13] The level of harm or morbidity is a direct consequence of not delivering the care. The greater the impact on the quality and outcome of care, the more important the issue.
3. *The issue must be treatable or modifiable, or best practice care readily ‘translatable’ into practice.*[13] We must prioritise those aspects of patient-centered care where the greatest good can be achieved. This refers to care practices that have high level evidence for reducing patient burden when put into practice. Similarly, those health care practices that are readily changeable by health care providers and systems should be allocated higher priority. Targeting the behaviour of treatment centre staff and the systems and process that support their behaviour may be a good place to start.
4. *Important to patients.* Consumer feedback is the cornerstone of patient-centered care. For a priority area to be truly patient-centered, it must be endorsed by the patient. [14]

Table 1 outlines those aspects of cancer care, within each of the six IOM domain of patient-centered care, which should be considered priority areas for the focus of our efforts.

Survey items must provide ‘actionable’ data

For a patient experience survey to be useful the items must be framed in such a way that they clearly translate into actions. Asking specific questions about the clinical care a patient has received during an appointment, or a series of appointments, may be more ‘actionable’ than exploring whether a particular aspect of care was

generally judged as adequate or not.[9,15] For example, it may not be ideal to ask patients “did the hospital do everything they could to help control your pain”, [16] as some patients believe that their pain is an inevitable aspect of cancer or untreatable, [17] and may report that the treatment team has done ‘everything they could’ to help. It may be more informative to ask patients to report on observable standards of care. For example, “Last time you had cancer-related pain, were you offered assistance at this clinic to treat your pain?” and “Did the pain treatment or assistance offered relieve your pain?”. Ensuring our assessments provide useful and actionable data that can be readily used by providers is paramount to improving quality of care. To ensure we are applying this approach it is necessary to revisit the items currently in use to measure the patients’ experience of cancer care.

What aspects of quality of care should we routinely measure?

Process and consequences of health delivery are important aspects of health care to measure.[13,18] Processes are particularly promising as they are in immediate control of health care providers.[15] Those processes of interest should [demonstrate a clear relationship to improved health care outcomes. We propose](#) three core processes that we believe are both promising and ‘actionable’ points in the delivery of patient-centered cancer care, and which should be considered for patient-reported measurement: 1) whether the patient is *asked* by a health care provider about their problems, preferences, and needs; 2) whether the patient is *offered help* when an issue is detected and 3) whether the patient experiences *relief of suffering* and delivery of care that is *consistent with patients’ preferences, needs and values*. Measuring these three indicators of quality across the six IOM domains of patient-centered care may provide a clear and coherent pathway for identifying deficits in care that can activate quality improvement activities.

Why should we measure whether patients are asked about their concerns, values and preferences?

Measuring quality of patient-centered cancer care should begin with an assessment of whether patients have been specifically *asked* by a health provider at the cancer treatment centre about their issues, values and preferences across the six domains of patient-centered care. *Asking* patients about their concerns values and preferences is important because:

1. An unknown issue or preference cannot be properly addressed

If an issue is not recognised it cannot be treated. Similarly, if a preference is not understood, it cannot be incorporated into an individual’s cancer care.

2. *We cannot rely solely on clinician judgement to recognise patients' issues, values and preferences.*

Not all health care professionals accurately recognise their patients' physical and psychosocial problems, medical decision making preferences, preferred treatment type, or information needs. Compared to patient self-reported symptom checklists, clinicians may underestimate the severity of common physical symptoms such as pain and fatigue.[19-21] Similarly, patients' anxiety, depression and distress may not be accurately detected by health professionals.[22-24] Concordance studies highlight that clinicians can have inaccurate awareness of their patient's preferences for involvement in treatment decision making,[25] and their patient's treatment and health care preferences.[26,27] Furthermore, clinicians do not always recognise that their patients may lack the necessary understanding of their situation, at various stages along the cancer pathway, to enable autonomous decision making.[28-30]

3. *We cannot rely solely on patients to initiate discussions with health care providers.*

Patients may be reluctant or unable to discuss their issues, preferences and needs without prompting from a health care provider. While 'active' patient participation (such as asking questions or informing health care providers without prompting) is associated with better health outcomes, many patients are not equipped with the knowledge or skills to actively engage with health professionals.[31,32] Patients do not always know which questions to ask. A variety of patient-related barriers to active engagement in cancer consultations have been identified. Barriers include i) poor health literacy, ii) lack of information or knowledge to enable participation in shared-decision making, iii) fear of distracting the doctor from treating the cancer, iv) belief that the clinician is too busy, v) belief that addressing a particular need is not a core component of the clinicians role, vi) belief that the doctor will inquire about important aspects of care, vii) desire to be a 'good patient', and viii) belief there is nothing that can be done to help a particular symptom.[33,34,17,35,36,28] Furthermore, encouragement by physicians to ask questions, by itself, does not appear to increase questions by advanced cancer patients. [37]

Why should we measure whether patients have been offered assistance when an issue is detected?

After becoming aware of the patient's issues and needs, if the answer from the patient suggests that they would like assistance, then it would be expected that this would be offered. Offering help is a fundamental indicator of quality because:

1. *Offering help is an integral reason for why health services were established.*

Offering care is the highest order obligation of the institution of health care.[38] Health care services were established with the goal of offering assistance to individuals to enable them to achieve their maximum health potential. Therefore, a quality health care system can be characterised by the offer of help being extended to those patients who are suffering and are in need.

2. *Offering help demonstrates caring*

The offer of help from a provider to a patient is an overt demonstration of caring. Offering help can demonstrate that the provider is interested in the patient, has listened to their needs, that they value their patient's well-being and quality of life, and they care enough to offer assistance. Offering help extends beyond the application of technical management of disease, to the cultivation of personal relationships that allow the patient to feel cared for,[32] can facilitate improved health care adherence and in turn improve patient outcomes .[39,40]

3. *Offering help enables patient self-determination of their health and health care*

The patient-centered approach is characterised by self-determination, and aims to provide patients with the resources to actively partner with health care providers to participate in their own care. As patients may not always want assistance and some treatments are not readily accepted by patients (eg opioids[17], counselling[41]) *offering* help provides individuals with the opportunity to accept or reject the assistance. Enabling patients to make autonomous decisions about their health care can ensure care is concordant with their values, needs and preferences. Patients who receive their preferred level of care are more likely to be satisfied with their consultation. [42]

Why should we measure whether patients report improved health care outcomes?

Finally, if the patient indicates that they would like assistance and it is provided, then it might be expected that the patient would report that the provided assistance did relieve their suffering, and/–or met their unmet need. and/or was consistent with their preferences and values. There is general agreement that exploring patient-reports about the outcomes of the care should be measured because:

1. *Measures the effectiveness of care delivery as experienced by the patient*

The final goal of quality care is the patient's health care outcomes. Given the personal nature of patient-centered outcomes, the patient is the arbitrator and in the best position to report on the extent that the help relieved their suffering and was consistent with their preferences, needs and values. [6]

2. *Allows focus on ineffective delivery of care.*

Exploring patient-reported health care outcomes alongside process measures allows their association to be examined.[18] This approach is very powerful for quality improvement as it allows us pin-point where in the care pathway poor outcomes originate, and focus our efforts accordingly. Given that process measures are very exacting measures of health care delivery, exploring process alongside outcomes helps to provide a balanced picture of health care delivery. That is, sometimes health care providers can 'get away with' not performing a particular step in the process, as a process may not always impact a patient's outcome.

Do existing patient-reported outcome measures (PROMs) 'measure-up'?

A variety of patient experience surveys are being administered by health care organisations to inpatient and outpatient populations to identify areas for quality improvement. While many surveys exist in the grey literature, making their retrieval and evaluation problematic, a recent systematic review of published surveys exploring patient-centered cancer care identified only one PROM (for non-small cell lung cancer patients) that explored all six patient-centered care domains.[43] Despite this, the field has clearly moved in the right direction, away from subjective measures of satisfaction with care, to more objective reports of experience of care. However, to our knowledge, no patient-report surveys routinely measure 'asking' 'offering' and 'reported benefits' across each of the six dimensions of patient-centered care.

Summary and next steps

If we wish to ensure treatment centres are accountable for, and responsive to, delivery of patient-centered care, we must ask specific questions about the process and outcomes of care. Cancer treatment centres should routinely survey their patients across each priority indicator within the six IOM dimensions to explore whether they were specifically asked by a health provider about their concerns, values and preferences; whether assistance was offered, and whether it provided relief from suffering, or was consistent with their preferences, needs and values. These results should be fed back to clinic staff in a timely manner, to enable the health care

service to target their quality improvement activities and track progress over time. However, further work to establish consensus regarding the priority areas that should be assessed is needed before widespread implementation of this approach. The priority areas presented in Table 1 are derived from a review exploring patient-centered care; as well as feedback from a panel of scientists, and 7 consumers (including one caregiver). Clearly, further consumer input into the refinement of these priorities is needed. Ensuring consumer consensus to our researcher-derived definition of optimal cancer care is required.

Understanding patient experiences can be used to identify inequitable delivery of cancer care, and also explore potential variation in care delivery between treatment centres. Understanding how the characteristics of a particular organisation can impact on cancer care delivery can inform what could be modified within an organisation. However, to ensure that we make much faster progress by engaging health care systems in the quality improvement process, we must first provide them with persuasive data.[44-46] There is a need for more studies exploring quality of patient-centered care to be published in credible peer reviewed journals, as scientific evidence is valued by clinicians, organisations and healthcare systems. [1,47] Publishing scientific evidence develops the evidence base, and stimulates further action and intervention studies. Intervention studies are only funded with competitive research funds when there is a strong evidence base for their need. Obtaining and publishing data about the provision of patient-centered care and quality improvement initiatives will provide influential information about what to do to improve the cancer treatment centres.

Table 1: Potential priority areas for patient-centered cancer care

IOM DOMAIN OF PCC	PRIORITY AREA	PREVALENT	BURDENSOME IF CARE NOT DELIVERED	TREATABLE	IMPORTANT TO CONSUMERS ?
Physical comfort	Pain	~ 59% of individuals during cancer treatment[48]	Reduced quality of life[49], participation in work[50] and other daily activities[51,52]	Pharmacologic interventions (eg. non-opioids, opioids, co-analgesics); non-pharmacologic interventions[53]	Yes[14]
	Fatigue	up to 91% of all cancer patients as a result of their cancer or treatment[54]	Reduced quality of life, participation in social activities, cognitive abilities, and employment status change [36,55]	Treat comorbid medical conditions and symptoms; pharmacologic interventions, non-pharmacologic (cognitive behavioural therapy, patient education; exercise)[56]	Yes[55]
Emotional support	Distress, anxiety	up to 45% of outpatients [57,58]	Reduced quality of life[59]	Psycho-educational approaches and psychological support, and pharmacotherapy[60]	Yes [61]
	Depression	~16% of outpatients [62]	Reduced treatment adherence [63], poorer physical outcomes [64]		
Enabling informed decision making	Adequate provision and comprehension of information to enable informed decision making	11-97% unmet meet information needs during treatment[8], inadequate discussion of treatment options,[8] poor comprehension of information[65]	Reduced ability to actively participate in decisions[66] Less perceived trustworthiness of the clinician [67,68]	Provider communication skills; provision of written information [70-72]	Yes[73]
	(eg prognosis, treatment and side effects)		Lower satisfaction with care[69]		

Respect for patients' preferences and values	Preferences for involvement in medical decision making	<p>40-64% mismatch between preference and actual experience of decision making[74]</p> <p>~42% do not receive preferred end-of-life care[75]</p>	<p>Increased decisional conflict, lower levels of satisfaction with the decision and the consultation, poorer well-being [74] [76,77]</p> <p>Receipt of more intensive end of life care, without significant impact on life span [75]</p>	Patient-centered communication [42], use of decision aids [78].	Yes [14]
Family and friends	Involvement of family and friends in consultations	<p>~12- 48% unmet need for information needs (eg patients illness status, caring for the patient, test and treatment)[79-81]</p> <p>~36% unmet need being involved in the decision-making process with patients [79]</p>	<p>Lower satisfaction with care[82]</p> <p>Shorter appointments without family present[83]</p> <p>Family provides reassurance, emotional support, information recall for patient, information provision to provider[83]</p> <p>Lower social support associated with poorer emotional well-being[58]</p>	Working with the 'family unit', not singular focus on the patient[84,85]	Yes[14]

Integrated, co-ordinated, continuous	Suitable appointment scheduling to enable access	13% medical oncology patients want more convenient appointment scheduling[86]	Disruption to daily life, including employment. Loss of income.[88] [89]	Offering a choice of appointment times[86]	Yes [100]
	Provision of sufficient information post-treatment to enable continuous self-care (eg. long term consequences, recovery time, symptoms to watch, contact person)	~30-50% post-treatment survivors report unmet information needs[8]	Unexpected symptoms impact on patient adjustment,[90] ability to care for oneself, poorer perceived quality of care[91-93]	Post-treatment information provision such as survivorship care plans[93], ensuring GP is also involved in long-term patient care.[98]	Yes [101]
	Provider-patient continuity	Patients see at least 13 clinicians during first year of diagnosis[87]	Impedes relationship building[94], lower patient satisfaction, less efficiency and safety[95-97]	Facilitate relational continuity[99]	Yes [97]

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