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The System for Patient Assessment of Cancer Experiences (SPACE): A cross-sectional study examining feasibility and acceptability

Running head: Patient Assessment of Cancer Experiences

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Abstract

Background: Continuous quality improvement in cancer care relies on the collection of accurate data on the quality of care provided. It is suggested that such an approach should: (i) measure the patient's care experience throughout the cancer trajectory; (ii) use items and response scales that measure concrete and specific aspects of care; (iii) minimise recall bias; (iv) minimise the burden placed on patients for providing data; (v) minimise administrative burden; and (vi) collect actionable data. The System for Patient Assessment of Cancer Experiences (SPACE) was developed to meet these objectives. This study describes the feasibility and acceptability of the SPACE in a sample of oncology outpatients.

Methods: The SPACE was examined in four medical oncology centres. Adult patients were approached by a research assistant prior to their scheduled consultation. Consenting participants completed the SPACE on a computer tablet. Items were tailored to the patient's cancer treatment phase.

Results: Of the eligible participants, 1,143 consented (83%) and 1,056 completed the survey (92%). The average time taken to complete the survey was 6 minutes 28 seconds. A large proportion of the sample indicated that the survey was acceptable (88-93% across three acceptability items).

Conclusion: This study demonstrates that the SPACE can be feasibly administered each time a patient comes to the oncology unit and is acceptable to patients. The SPACE could be used to quantify the care experiences which patients receive during their cancer care. The resulting data could be used to set benchmarks and improve the performance of cancer clinics.

Introduction

Why is it important to measure consumers' perspective of the cancer care experience?

The Institute of Medicine defines high quality health care as care which is safe, effective, timely, patient-centred, efficient and equitable[22]. Over the past 20 years there has been an increased focus on assessing the patient-centredness of care, particularly in cancer. Patientcentred care is a broad concept which covers responsiveness to patients' needs, values and preferences across a range of domains including physical comfort, emotional support, information and education, involvement of significant others in care, continuity, coordination and access. It is the most amenable of all components of quality to assessment via patient self-reported experiences. There are persistent gaps in the provision of patient-centred care in oncology, including a lack of patient involvement in decision making[11], high rates of medical errors [5, 10] variations in care quality across treatment centres [32], and suboptimal detection and management of physical symptoms and psychosocial concerns[18, 35]. These gaps cannot be effectively addressed without a mechanism for measuring the delivery of patient-centred care in a standardised way. Quantitative data on quality of care allows priority areas to be identified and the impact of strategies to address these gaps to be monitored. Development of a comprehensive and integrated system to assess patient experiences, which can be implemented within and across cancer treatment settings, is required if we are to achieve optimal health care delivery. There are several dimensions that a system of patient assessment would need to cover in order to deliver on such objectives.

Requirements for a comprehensive System for Patient Assessment of Cancer Experiences

To achieve change within the health care system in an efficient manner, we propose there are a number of principles, which should be followed to develop a comprehensive measure of patients' cancer experiences. The System for Patient Assessment of Cancer Experiences (SPACE) was developed based upon the following principles.

Measure the patient's care experience throughout the cancer trajectory: Often assessments of care focus on a few select phases of the cancer trajectory, such as diagnosis, treatment or follow-up[3, 7, 25]. High quality care is derived from the entire care experience, rather than a specific phase of care. A mechanism for assessing quality in a way which allows patients to report on each phase of cancer care they experience, from diagnosis to end-of life, is needed.

Use items and response scales that measure concrete and specific aspects of care: Measures of satisfaction provide a subjective indication of the patient's experience. However, expectations of health care may influence how satisfied patients are with care received. It is also conceivable that two patients may receive similar care, but provide very different responses regarding satisfaction depending upon their preconceived expectations of the care provided. Factors such as age, health status and education have been shown to influence patient's ratings of satisfaction[20]. Therefore, assessment of care experiences should go beyond that of general patient satisfaction. Assessing patient experience has the potential to overcome the limitations of satisfaction surveys. By asking about the receipt of concrete and specific aspects of care, the impact of patient expectations on responses can be minimised[12, 23]. We propose that selection of components of care for assessment should be based on one or more of the following principles: care which is safe, ethical, evidence-based and/or patient-centred. It is also important that the elements being assessed: (i) are relevant to cancer

patients; (ii) have the potential to impact patient outcomes; and (iii) have capacity to be improved. Examining whether individual aspects of care were received by each patient provides an objective assessment of care, i.e. the patient did or did not receive a particular component of care. Assessing whether the component of care was perceived as needed / wanted by the patient can ensure that the data provides an indication not just of care delivered, but of degree of patient-centredness.

Minimise recall bias: Previous research indicates that the length of time between an event occurring and its accurate recall is crucial[13]. Existing patient experience measures often examine overall perceptions of quality of care after a patient's cancer treatment has concluded[4]. This increases the likelihood of inaccurate recall as patients are being asked to reflect on their experiences after some time has passed. Inaccurate recall may be exacerbated by memory problems, which are a frequently reported side effect of cancer treatment[21]. It is important that efforts are made to ensure that the findings are as accurate as possible. The time between the event and collecting information should therefore be minimised.

Minimise the burden placed on patients: The amount of time requested of patients to complete questionnaires should be a primary consideration. Wherever possible the number of questions asked should be minimised and should not place significant burden on the patient. This need is reflected in the literature through the ongoing development of short-form questionnaires[24]. Efforts should be directed at minimising time requested of patients while targeting components of care which maximise the data's utility within a clinical setting.

Minimise administrative burden: Despite ongoing innovation in electronic technologies, penand-paper surveys and manual methods of data analysis continue to dominate the field. For example, only 20% of participants who completed a state-wide outpatient cancer clinic survey did so online, meaning 80% of responses were completed on a paper survey requiring manual processing [7].These methods are not an economical use of time or money. Electronic data collection has significant benefits for treatment centres and patients. Computer algorithms can be used to automatically summarise data. This allows data to be fed back in real time. Cancer patients find electronic data collection to be both acceptable and feasible, irrespective of their age or socio-economic class[1, 15]. Electronic methods can also be used to allow for survey translation in to different languages, adjust font size for the visually impaired and tailor questions based on participant responses.

Collect actionable data: The data collated from patient experience measures requires real world applicability. Collecting data specific enough to be 'actionable' when fed back to the health service is an important aspect of this. For example, the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS), which is widely used across the United States asks "During this hospital stay, how often did nurses explain things in a way you could understand?", with response options of: "Never", "Sometimes", "Usually", "Always"[19]. Provided with feedback that, for example, 30% of patients state that nurses 'never' or 'sometimes' explain things in a way they could understand, it is difficult for a health service to identify what should be targeted for improvement. For instance, did patients require simpler terminology, were there particular topics that were more difficult to understand, was information only provided verbally etc. In contrast, a clearer course of action is possible if a service received feedback such as 30% of patients reporting that their doctor "never" or "sometimes" provided them with information about the long-term side effects of a particular

treatment. Similarly, the NSW Outpatient Cancer Clinics patient survey asks "Did you have confidence and trust in the health professionals?"[7]. Feedback that, for example, 20% of patients had no confidence or trust in the health professionals, would be difficult for health services to determine how to address. The importance of providing services with actionable data was one of the key criticisms of patient satisfaction surveys[26], and the development of patient experience surveys has come some way to overcoming this. Providing oncology clinics with summary data of their performance in specific areas can act as key performance indicators for the patient experience. While it is likely that a patient will interact with several care providers including nurses or allied health staff; their overall care should be monitored by their primary physician. Using linking data such as patient names or medical record numbers can allow group data to be linked to their primary physician. This can enable the assessment of individual clinician or team performance and enhance accountability. Convincing oncology clinics to make changes to the care they provide will require adequately sampled data to ensure the results accurately reflect the clinic functioning. The number of patients required to achieve this with confidence can be ascertained through sample size and power calculations. Large samples of grouped data increases the probability that the findings do not represent outliers but rather provide accurate information regarding patients' perceptions of care.

Aim: To describe the: i) development; ii) feasibility (i.e. consent rates, completion rates, and time taken to complete) and iii) acceptability of the SPACE in a sample of oncology outpatients.

Methods

Development and design of the SPACE

An extensive literature review of current patient satisfaction surveys and patient experience surveys was performed to inform and develop the SPACE items. Examples of examined surveys include the National Cancer Patient Experience Survey[33] and the New South Wales Patient Perspectives Survey[6]. Supportive and psychosocial care guidelines were also consulted[8, 9, 27-29]. Items were initially mapped to key domains of patient-centred care, as defined by the Institute of Medicine and Picker Institute[22, 30]. These items were then further mapped to phases across the cancer trajectory. To meet the requirements of a comprehensive patient assessment of their experiences with cancer care as outlined above, the SPACE possessed the following qualities:

1. Measure the patient experience of care received throughout the cancer trajectory. The SPACE was built using complex branching algorithms to allow questions to be tailored for participants based on their phase in the cancer trajectory. This allowed for the survey to be administered to patients at any phase. A series of branching questions determines where patients should be directed in the survey (see **Figure 1**; red text not visible to patients). Patients received each module relating to a specific phase of care only once. There were six modules (A-F) relating to the different phases of care (see Appendix 1). There were also fouritems that could be administered to patients multiple times if they had already completed the relevant treatment module but were surveyed before moving on to the next phase of care (see repeating module in Appendix 1).

<<Insert Figure 1 here>>

2. Use items and response scales that measure concrete and specific aspects of care. Aspects of care which were concrete, specific and actionable were the focus of the survey items. The response scale captured both whether a patient received a certain aspect of care and whether the care they received (or didn't receive) aligned with what they wanted. The possible responses to survey items were: 'Yes, and I wanted this'; 'Yes, but I didn't want this', 'No, but I wanted this', or 'No, but I didn't want this'.

3. *Minimising recall bias*. As the survey was tailored to the participant's current phase in the cancer care trajectory, the items were specific to the most recent care they received. This minimised the time between the care being received by the patient and their reporting of their experience. While delivering the survey immediately after the patient's appointment would be optimal in terms of recall bias, this increases the burden on patients, as outlined below.

4. *Minimises the burden placed on patients for providing data*. Several strategies were used to help minimise the burden on patients. Firstly, they were invited to participate while waiting in the clinics or while undergoing treatment. This allowed them to complete the survey during time they would already be in the hospital, ensuring they did not need to dedicate additional time after their appointments or at home. Secondly, the tailored survey presented patients with only the questions that were directly relevant for them. Lastly, a survey login was used to identify patients which allowed the computer platform[31] used to administer the SPACE to determine which questions the patient had already completed on previous visit/s to ensure they did not get questions repeated unnecessarily, such as their demographics.

5. *Minimise administrative burden*. Touchscreen computer tablets were used for data collection. The use of an electronic survey enabled the complex branching needed to tailor the survey questions. Furthermore, the use of this technology allowed for instantaneous results to be uploaded to the server and examined by the researchers.

6. Collect actionable data. The SPACE was developed with the intention to summarise data across groups and provide this information as feedback to clinics. The aspects of care that were assessed (principle 2) were intended to be areas where actionable change was possible once data were relayed back to treating centres. This capability of the SPACE was not directly tested in the current study, however, it is intended to be examined through future use of the survey.

Feasibility and Acceptability assessment

Setting

The survey was administered in four oncology units, three of which were located in public hospitals and one located in a private hospital, in NSW, Australia.

Sample

Patients who were attending for treatment in the day treatment centres or for an outpatient appointment with their oncologist were approached to participate. Eligible patients included those who were: attending one of the participating clinics; had a diagnosis of cancer; aged over 18 years; able to complete an English language survey; and able to provide informed consent. Patients who judged to be too ill or distressed were not approached to participate in the study.

Procedure

The study was conducted from September, 2017- March, 2018. In the outpatient clinics, patients were approached by a research assistant (RA) prior to their scheduled appointments. In the day treatment centres, patients were approached after their treatment had been set up. Patients were provided with a verbal overview of the study and offered an information statement. Those who indicated willingness were provided with the computer tablet to commence the survey. Implied consent was obtained through initiation and completion of the survey.

Patients could be approached on multiple occasions regardless of whether they had previously declined or accepted participation during previous visits. Patients were asked to input their initials, birth date and gender to the survey login page. This information created a unique login for each participant and was used to link survey results together.

Study data were collected and managed using REDCap electronic data capture tools [17] hosted on a secure server at the Hunter Medical Research Institute (HMRI). No study data were stored on the computer tablets used for data collection.

Measures

SPACE survey. As described previously.

Demographics. Patients self-reported their: home postcode, highest level of education, country of birth, cancer type, cancer stage at diagnosis and how long ago they were diagnosed. Patients' age and gender were extracted from their login details. Patients only completed the demographic questions once; the first time they completed the survey.

Feasibility. Survey feasibility was measured through: consent rates; completion rates; and time taken to complete. RAs recorded the number of patients approached and the number consenting via recruitment log sheets. For patients that did not consent, RAs asked the patient if they could record their gender, age and whether the patient had previously completed the survey. For consenting patients, RAs were asked to record whether the participant had any questions about the survey (e.g. how long the survey would take or what happens if they get called in to their appointment) and whether they needed any assistance with the computer tablet (e.g. required instruction using the touchscreen or inputting responses). A survey was considered complete if no answers were missing from the appropriate module. Completion time was automatically recorded using the survey program.

General Acceptability. Patients were asked three acceptability questions the first time they completed the survey, which had a four point Likert response scale (response options: *strongly disagree, disagree, agree* and *strongly agree*). Participants were asked to think about the survey they just completed and indicate whether they believed:

- It was easy to complete
- Completing a short survey before each appointment is reasonable if it helps improve care
- Most questions were important for cancer patients.

Data analysis

Participant characteristics were calculated using counts and percentages. Counts and percentages were also calculated for: consent, completion, the proportion of patients who asked questions about the survey, the proportion of patients who required iPad assistance and the acceptability questions. Time taken for the overall survey and individual modules was averaged for the sample and rounded to the nearest second. All statistical analyses were conducted using Microsoft Excel, 2013.

Results

Feasibility of the quality of care survey

Characteristics of consenting patients can be found in **Table 1.** Patients were screened for eligibility on 1,481 occasions, with the patient assessed as eligible to participate on 1,379 occasions (93%). Of the eligible occasions, 1,143 involved a consenting participant (83%) with 1,056 surveys completed (92% of 1,143 consenters). Of the recorded non-consent occasions (n=236), 40% had previously completed the survey (n=95). Of the completed surveys, 804 patients completed the survey once, 80 completed it twice and 27 completed it three or more times. Only 9% of consenting patients asked the research assistant questions relating to the study (n=98) and 19% (n=216) required assistance using the touchscreen computer. As the survey underwent minor iterations during data collection as part of the development process, timing data was not directly comparable for all data. Timing data was available for a total of 785 completed surveys. The total average time taken to complete the survey was 6 mins 28 secs, which varied from 1 min 31 secs to 6 mins 5 secs for the different survey modules (**Table 2**).

<<Insert Table 1 here>>

<<Insert Table 2 here>>

Acceptability of the quality of care survey

A total of 656 patients (67%) were administered the acceptability questions. **Table 3** shows the acceptability for the survey to those who completed it. Ninety-three percent of the participants indicated that they agreed or strongly agreed that the survey was easy to complete (module range: 87%-97%). In addition, 88% agreed that completing a short survey before each appointment was reasonable if it helped to improve cancer care (module range: 85%-94%); and 90% agreed that most of the questions were important for cancer patients (module range: 85%-100%).

<<Insert Table 3 here>>

Discussion

Overview

This study examined the SPACE, the first comprehensive and tailored assessment of care for cancer patients which spans the entire cancer trajectory. The findings from this study indicate that the SPACE is both feasible to administer in cancer clinics and acceptable to patients.

Feasibility and acceptability of the survey and its compatibility with proposed development principles

When assessing the unique characteristics of the SPACE within the cancer clinic, both the questionnaire and the recruitment methods performed well. Consent and completion rates were high (>80%). The SPACE is therefore feasible to administer and complete in oncology clinics. The overall high completion and acceptability rates highlight the relevance of the SPACE to cancer patients throughout the various phases of the cancer trajectory. The SPACE is able to measure care across the phases of the cancer trajectory (*principle 1*). Furthermore, the response scale is one which can be answered and meaningfully interpreted (*principle 2*).

The manner in which modules were administered meant that the SPACE required only an average of 6.5 minutes to complete. Asking only those questions relevant to the participant's phase of the cancer trajectory can minimise the time burden placed on participants (*principle* 4). This method can also overcome issues related to recall bias[13], which is a significant limitation of many self-report surveys that rely on patients in follow-up to report on their early cancer care. The large proportion of patients who reported that completing a short survey before each appointment was reasonable suggests that this approach can be feasibly implemented in a clinical setting (*Principle 3*).

Almost one quarter of the sample required some assistance with the computer tablet. This may in part be due to the representation of older patients in this sample. The lack of familiarity among some older people with this technology[2] is often reported as a potential barrier to this method of data collection [16, 34]. It is important to note that the required assistance was primarily limited to instruction on use of the touchscreen tablet prior to commencing the survey. While some initial assistance from hospital staff may be required for those that are not familiar with computer tablets if this survey was implemented in to practice, most participants were able to complete the SPACE without any assistance. This aligns with our previous research which found that computer tablets are an acceptable and feasible mode of data collection in health care settings[1]. The use of this technology did not appear to hinder completion of the survey in the current study. Therefore, using touchscreen computer tablets for SPACE administration appears both acceptable and feasible (principle 5). It should be noted that while research assistants were employed in the current study in order to ensure participants provided informed consent for this research, SPACE has been designed with a view to eliminating the need for RAs if a cancer centre wished to use SPACE on an ongoing basis. The next phase of this research program involves testing feedback mechanisms, such as providing reports of the survey results to clinic staff, and determining the effectiveness of feedback in improving quality of care. Should improvements in quality be achieved, the next step would be to explore the most appropriate methods for implementation of SPACE into routine practice, including resource implications.

Implications for clinical practice

The SPACE can be used as a tool for advancing quality control and assessment of care received by cancer patients. Individual patient data obtained via the SPACE can be fed back to clinicians to highlight areas where their patients perceive they are receiving sub-optimal care. De-identified group data can also be presented to allow an examination of the performance of individual clinics and to support benchmarking across centres (*principle 6*). If adapted as part of a clinic's usual functioning, the SPACE data can be compiled to assess an

individual clinician's performance. Dependent on the healthcare system in which SPACE is being used, there is the potential to attach key performance indicators (KPIs) to defined quality of care measures at both the clinician and clinic level, although it is essential to first develop mechanisms for feedback that are acceptable to stakeholders. Each of these potential uses can help ensure there is accountability in delivering high quality, patient-centred cancer care.

While we did not collect routine acceptability data from clinicians, clinicians were largely supportive of the implementation of SPACE within their cancer centres. The study team used several strategies to reduce the impact of the study on clinical services, including working with cancer centres to attend clinics or day treatment facilities on agreed days/times that were most suitable, approaching patients only after they had checked in for their appointment or had commenced their treatment session and providing participants the option of exiting the survey early if they were called for their appointment. As this was a pilot study to determine acceptability and feasibility, we collected limited self-report data from the patient. If SPACE was adopted into clinical practice, there is capacity for the data to be linked to an individual's medical record in order to obtain greater specificity about their diagnosis and treatment (see Dudgeon et al 2012 [14] for an example of how this could be achieved in practice).

Limitations

The study should be considered in light of its limitations. The generalisability of this sample is unclear as data were collected from only four sites. While the large number of patients approached may have somewhat offset the small number of clinics involved, it is important to consider variations between sites and location and how this may impact the feasibility of the assessment system. In addition, the survey may be limited as the branching questions used to direct patients to the relevant the SPACE module may not be inclusive of all individual patient trajectories. Extensive efforts were made to ensure these questions were as inclusive of as many cancer care phases as possible, while not sacrificing the specificity of the survey questions. However, given the complex nature of cancer and its treatment, it is difficult to categorise these questions in a way which is inclusive of all patient circumstances. Nevertheless, the high completion rate in this study demonstrate that the survey questions were applicable to a large majority of patients.

Conclusion

This study found the SPACE to be feasible and acceptable when administered to oncology patients. The SPACE can be administered to patients with any cancer diagnosis and across the entire cancer trajectory. The SPACE can be used in future studies to quantify the care experiences of patients throughout their cancer care. The data can be used to benchmark and improve the performance of cancer clinics.

Conflict of Interest: The authors do not have any conflict of interest to report.

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Author Contributions: RSF, MC, HT and AP were involved in conceptualisation of the study. RSF, BH and HT developed the methodology and oversaw data collection. BH performed the data analysis. All authors were involved in drafting, review and editing the manuscript.

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