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Measuring the Quality of a Childhood Cancer Care Delivery System: Assessing Stakeholder Agreement

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ABSTRACT

Objectives: We described previously the development of a set of quality indicators (QIs) of a childhood cancer system in Ontario, Canada. The purpose of this study was to determine the acceptability of the proposed set of QIs among stakeholders of the childhood cancer system. **Methods:** A modified Delphi method was used to assess stakeholder agreement on the value of the proposed QIs. A QI evaluation survey was mailed to a stakeholder group of 23 multidisciplinary health care providers, survivors, parents, and policy-makers who rated each QI on specific criteria. Prior to an in-person consensus meeting, the distribution of scores was provided to panel members. At the meeting, QIs were reevaluated and discussed in three successive rounds. QIs with 80% or more of panel agreement were considered endorsed. **Results:** Overall, 20 QIs were endorsed by the panel, measuring all seven quality dimensions of Ontario's Cancer System Quality Index framework. Five QIs were endorsed by 100% of

the panel as follows: Five-year event-free survival, chemotherapy admission delay, drug availability, sufficient multidisciplinary staff, and parent satisfaction. Although none of the QIs relating to end-of-life or Satellite care were endorsed, panel members emphasized the need to measure these components of the system. **Conclusions:** Standardized implementation of the 20 pediatric cancer QIs endorsed by the multidisciplinary stakeholder panel will provide ongoing monitoring of various dimensions of system quality and the development of benchmarks over time, greatly augmenting the ability to identify needed system improvements across populations and jurisdictions. **Keywords:** consensus, Delphi technique, health care, neoplasm, pediatric, quality improvement, quality indicators.

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Introduction

Although cancer remains the most common disease-related cause of death among children in North America [1–4], there is no well-defined set of quality indicators (QIs) of a childhood cancer system against which any system can be compared. QIs can be used to inform and influence policy or funding, alter clinical practices and behaviors of health care providers, increase the general understanding in the community, and improve the quality of the system [5]. For most areas of health service delivery, quality assessment is evidence-based, yet limited evidence exists for quality measurement in pediatric oncology [6,7]. While QIs and quality assessment frameworks for the cancer control system for adults have been developed [8,9], a set of indicators to assess the quality of a childhood cancer system has not been identified in any jurisdiction in Canada or internationally [6,7].

The Pediatric Oncology Group of Ontario (POGO) is a collaborative consortium of the five specialty pediatric cancer programs in academic tertiary hospitals in Ontario, Canada, and the

community hospitals and cancer centers that deliver POGO provincial pediatric oncology programs. These programs include a system of Satellites, providing devolved care, AfterCare clinics, for the long-term follow-up of pediatric and adult survivors, and expert pediatric oncology Interlink Community Nurses (who support children and families in the hospital, community, and at home). POGO is mandated to identify areas for cancer system development to the provincial Ministry of Health and Long-Term Care (MOHLTC) and operates in ongoing collaboration with families of children with cancer, survivors, corporate and private benefactors, and volunteers. Since 1985, the organization has actively and prospectively collected standardized sociodemographic, diagnostic, therapeutic, and outcome data on each new case of childhood cancer diagnosed and treated in the province through its population-based Networked Information System (POGONIS) [10].

In a companion study [6], we report the development of a proposed QI set for the childhood cancer system in Ontario on the basis of a systematic literature review and expert consensus. QIs were to be scientifically sound and valid, reflect an important

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health issue or aspect of system-functioning, relevant to quality improvement and health care accountability, aligned with the childhood cancer mission and strategic objectives of the system, interpretable and feasible, address a priority area, and meaningful and of interest to key parties [6]. The purpose of the current study was to assess the acceptability of the proposed set of QIs for the childhood cancer system among provincial stakeholders.

Methods

A modified Delphi process was used to assess stakeholder agreement on, and acceptability and prioritization of, 33 proposed QIs. This is a validated method using structured facilitation to obtain feedback and determine group consensus by synthesizing opinions [11–13] “when published information is inadequate or non-existent” [14]. This study received approval by the Research Ethics Board at McMaster University, Ontario, Canada.

QI Selection

In a companion study [6], a subset of 33 QIs was developed (see Appendix B of companion study in Supplemental Materials found at <http://dx.doi.org/10.1016/j.jval.2013.02.016>), measuring the seven quality dimensions of the Cancer System Quality Index (CSQI) framework (see Table 4 of companion study) [15].

Modified Delphi Panel Assembly

A panel of 23 individuals representing each of the key stakeholder groups was invited to participate. These groups were multidisciplinary health care providers, who may use the findings to improve the quality of care provided to children with cancer; childhood cancer programs, which will implement QIs and adapt to findings; survivors of childhood cancer and parents of children who had cancer, who may use the findings to raise awareness, promote advocacy, and make informed health care decisions; and policymakers and decision makers, who are interested in system performance measurement and monitoring.

Purposive sampling was used to select at least one representative from each stakeholder group. Provincial representation was sought whereby each of the five tertiary programs nominated one individual from each of the following discipline groups: physician, nurse, behavioral practitioner, allied health professional, and administrative/hospital manager. Tertiary programs also selected one “must-have” individual to represent each program. The final panel consisted of 23 participants: 17 health care providers, including six pediatric oncologists, a pediatrician from the Satellite program, four nurses from tertiary, Satellite, and Interlink programs, four behavioral practitioners (two social workers, one neuropsychologist, and one clinical psychologist), and two allied health professionals (one pharmacist and one physiotherapist); two tertiary hospital administrators/managers; one adult survivor of childhood cancer; two parents; and one policymaker from the Ontario MOHLTC.

Mailed Survey

Each panel member was mailed a survey and rated each QI on two criteria (meaningfulness and importance) by using a seven-point Likert scale (where 1 = “not meaningful” or “not important” and 7 = “very meaningful” or “very important”). The two criteria items for QI scoring were adapted on the basis of a recent modified Delphi process assessing stakeholder acceptability of adult cancer end-of-life care QIs [16] and assessed the meaningfulness (Does the indicator truly measure an aspect of Ontario’s pediatric cancer system?) and importance (Does this indicator reflect an important issue for this system?) of each QI.

The survey presented each QI with operational definitions, rationale for selection as a potential system QI, and measurement specifications (Fig. 1). Panelists were also able to provide comments on each QI.

Modified Delphi Panel Consensus Meeting

A full-day, in-person, multiround, iterative consensus meeting, facilitated by an external consultant, was undertaken to assess stakeholder agreement and acceptability of the 33 QIs. One week prior to the meeting, individualized scoring reports were mailed to each panel member, containing aggregate and individual respondent scores for each QI. Panel comments were also summarized anonymously in the reports.

At the meeting, panelists were presented with key considerations for QI endorsement. First, QIs were to be endorsed on the basis of their meaningfulness and importance. To capture highly important, relevant, and meaningful QIs, including those for which standardized data collection may not yet be established, issues of feasibility and resource implications were not to be considered. Panel members were also asked to use a systems-level perspective in evaluating QIs, rather than an individual center or health care provider perspective. Although a specific target number of QIs was not set, a high level of panel agreement was desired.

During each round of QI rating and discussion, panelists were asked to select QIs that they would endorse as an indicator of the quality of Ontario’s childhood cancer system. Anonymous responses were provided on individual electronic devices, aggregated, and displayed. QIs approved by at least 80% of the panel were considered endorsed.

Analysis

Means, medians, and SDs of survey scores were calculated for both meaningfulness and importance by using Statistical Analysis System software (version 9.1). For each QI and each criterion, scores of 6 to 7 were categorized as “very meaningful/very important,” 3 to 5 as “neutral meaningfulness/neutral importance,” and 1 to 2 as “not meaningful/not important,” and the percentage distribution for each score was generated.

Based on the mailed survey, panel agreement was assessed by using a disagreement index, calculated as the 30th to 70th interpercentile range divided by the interpercentile range adjusted for symmetry, as defined by the RAND working group [13,17]. This disagreement index describes the dispersion of individual scores, with scores of more than 1 indicating disagreement. Levels of panel agreement were also established on the basis of the proportion of panelists who scored the QI within one of the three categories of meaningfulness and/or importance, where 70% or more of panel members scoring within one category of meaningfulness/importance indicated “high agreement,” 60% to less than 70% indicated “moderate agreement,” and 50% to less than 60% indicated “low agreement.” The discussions were audiotaped, transcribed verbatim, and reviewed for common themes.

Results

Mailed Survey

Overall, 22 surveys were completed (96% response rate)—one panel member (parent) declined participation because of time constraints. Figure 2 summarizes the initial survey rating of the 33 QIs on their overall levels of meaningfulness and importance. QIs were scored highly, with a median score range of 4.5 to 7 (Table 1). Based on median scores, 19 QIs (58%) were rated as

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