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Parent Perceptions of Team-Delivered Care for Children with Advanced Cancer: A report from the PediQUEST study

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Abstract

Context: Childhood cancer care is delivered by interprofessional healthcare teams however little is known about how parents perceive overall team-delivered care (TDC).

Objectives: We sought to describe parent perceptions of TDC and associated factors, including care rendered by individual clinicians, teamwork, information consistency, and patient and parent characteristics.

Methods: Cross-sectional surveys were distributed to parents of 104 children with recurrent/refractory cancer enrolled in a multi-site symptom management trial. The primary outcome, TDC, was parent report of care quality delivered by the child's care team during the preceding 3 months. Likert scaled items (excellent/very good/good/fair/poor) queried care quality delivered by individual clinicians, perceived teamwork and other factors. Factors associated with parent perceptions of "excellent" TDC were identified using Fisher's Exact test.

Results: Eighty-six parents (83%) responded. Over the preceding 3 months, 63% (n=54) of parents reported excellent TDC. However, only 47% (n=40) described their care team's teamwork as excellent. Approximately one-quarter (24%) described care rendered by their child's oncologist as less-than-excellent. Among parents who reported psychosocial clinician involvement (71%, n=60), only 43% described this care as excellent. Individually, excellent care from each clinician type (oncologist, psychosocial clinician, primary nurse) was associated with excellent TDC (all p 0.001, no correction for multiple comparisons).

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Conclusion: Among parents of children with advanced cancer, more than one-third report less-than-excellent TDC. Additionally, less than half report excellent teamwork, and ratings of care rendered by individual clinicians are highly variable. Findings suggest interventions are needed to enhance interprofessional teamwork in the care of children with advanced cancer.

Keywords

Psychosocial Oncology; Childhood Cancer; Pediatric Oncology; Interdisciplinary Care; Team-Delivered Care; Multidisciplinary Care; Interprofessional Healthcare Teams

Introduction:

Caring for children with advanced cancer requires a patient-centered approach that identifies and addresses physical symptoms and psychosocial distress.¹ Thus, children with advanced cancer may benefit from the perspectives of multiple professionals operating from different disciplinary lenses, including oncology, nursing, social work, psychology, palliative care, physical therapy, chaplaincy, and child life, among others.^{2–8} These professionals are often conceptualized as belonging to an interprofessional healthcare team.⁹ Elements of excellent teamwork, including effective coordination and developing shared mental models, have been shown to enhance patient safety and healthcare quality.^{10–13} However, relatively few approaches to measuring teamwork in healthcare settings incorporate patient or family voices.¹⁴ Experience of care is one of the three core tenets of the Institute for Healthcare Improvement's Triple Aim, and an important component of achieving high quality healthcare.¹⁵ We sought to explore factors potentially associated with parent perceptions of team-delivered care (TDC), with a goal of identifying targets for intervention. We hypothesized that parent perceptions of individual oncologists' and non-physician clinicians' care quality would be associated with perceptions of TDC quality.^{16,17} We examined potential differences in perceptions of TDC among parents of children with different types of advanced cancer and differences in perceived symptom burden. We further hypothesized that perceived teamwork among members of the care team, receipt of consistent (versus conflicting) information, and parent demographic factors such as gender, education, race, and ethnicity may be associated with parent perceptions of TDC quality.

Methods:

The Pediatric Quality of Life and Evaluation of Symptoms Technology (PediQUEST) study was a pilot multicenter randomized trial of a supportive care intervention for children with advanced cancer.¹⁸ The primary outcome was use and impact of the PediQUEST software platform, which collected patient-reported outcomes and generated feedback for providers (<https://clinicaltrials.gov/ct2/show/NCT01838564>). Secondary objectives included understanding parents' characterizations of their child's medical team with regard to collaboration and care delivery.

Eligible patients were aged two years or more with progressive, recurrent, or refractory cancer for two or more weeks, had an English-speaking parent, and received medical care at one of the three participating National Cancer Institute-designated cancer centers between

December 2004 and June 2009. Respective institutional review boards at each site approved the study.

Study Instrument and Administration

The Survey About Caring for Children with Cancer (SCCC) was designed to elicit parents' perceptions of their child's illness and medical care.¹⁹ As previously described, key domains were identified through a literature review and focus groups with parents and medical providers. Previously validated items were used whenever feasible, with de novo items added. The comprehensive survey was pretested to evaluate content, wording, cognitive validity, and response burden. Participating families completed self-administered pencil-and-paper surveys. One parent per family completed the survey, and a \$5 coffee card incentive was included with the SCCC. Parents who did not respond within two weeks received two additional reminders. While the SCCC was administered at several time points to evaluate parent perspectives longitudinally, for the current study, we evaluated baseline responses obtained upon study enrollment.

The survey section of interest for the current analysis is "Caregiver-Family Relationship," which asked parents to describe the involvement of medical, nursing, and psychosocial professionals, perceived quality of care delivered by each team member, and perceived success of team collaboration, including consistency of communication. We sought to identify factors associated with parent perceptions of excellent TDC over the preceding 3 months (primary outcome), defined as a response of "excellent" to the item "Overall, how would you describe the quality of care delivered by your child's care team during the past 3 months?" Answer choices for this item were "excellent," "very good," "good," "fair," "poor." To assess parent perception of recent symptom burden in their ill child, parents were asked, "Overall, which of the following describes the amount of suffering your child is experiencing as a result of his/her symptoms? Would you say s/he is suffering:" "a great deal," "a lot," "somewhat," "a little," and "not at all." Responses were dichotomized as "high suffering" ("a great deal"/"a lot") versus "low suffering" ("somewhat," "a little," or "not at all). For involvement and perceived quality of care delivered by each clinician team member, parents were asked to respond to the item: "How would you describe the quality of care delivered during the past 3 months by each of the following members of your child's care team? For each team member, would you say the care has been excellent, very good, good, fair or poor?" Team members listed included the primary oncologist, outpatient clinic primary nurse, hospital primary nurse, and child's psychologist/social worker (psychosocial clinician). Respondents could select from the following answer choices for each professional: "excellent," "very good," "good," "fair," "poor," or "not involved." We hypothesized that positive ratings of individual clinicians' care quality would be associated with parent perceptions of excellent TDC. Clinician involvement was operationalized as "excellent" involvement versus "less-than-excellent" involvement (combining responses of "very good," "good," "fair," and "poor"). Parents who indicated "no involvement" of a particular clinician type (e.g. hospital primary nurse) were excluded from analyses involving the quality of care rendered by that clinician type. We hypothesized that perceptions of teamwork would be highly associated with perceptions of TDC. Parents were queried directly about their perception of teamwork with the item "During the past 3 months, how

well would you say your child's caregivers worked together as a team? Would you say the team work was:" with response choices of "excellent," "very good," "good," "fair," and "poor." Teamwork was dichotomized as "excellent" versus "less-than-excellent." We also hypothesized that receiving consistent (versus conflicting) information from care team clinicians would be associated with parent perceptions of excellent TDC. Receiving consistent information was defined as an answer of "rarely" or "never" (versus "sometimes" or "often") to the item "During the past 3 months, how often have you received conflicting information from different members of your child's care team?" We likewise hypothesized that parent characteristics, including gender, race, ethnicity, and educational attainment, may be associated with parent perceptions of TDC. All parent characteristics were self-reported. We dichotomized race as white versus non-white, and ethnicity as non-Hispanic/Latino versus Hispanic/Latino. We dichotomized educational attainment as greater than high school education versus high school education or less.

Statistical analysis:

We used descriptive statistics, including frequencies, proportions, medians, and ranges, to characterize the cohort of parent respondents, their children, the sites of childhood cancer care, the professionals who contributed to the child's medical care, and parent-reported care quality and communication consistency. No effort was made to impute missing data. Fisher's exact test was used to examine associations between potentially modifiable factors (perceived burden of suffering from child's symptoms, perceived quality of care from oncologists, primary clinic/hospital nurses, and psychosocial clinicians, perceived teamwork, and perceived information consistency) and the primary outcome (reporting excellent TDC quality in the preceding 3 months). Given a modest sample and the exploratory nature of the analysis, we did not create more complex multivariable models. Two-sided p-values ≤ 0.05 were considered statistically significant. SAS software version 9.4 (SAS Institute Inc., Cary, NC, USA) and STATA/SE version 15.0 (STATA Corp., College Station, TX, USA) were used to perform analyses.

Results:

One hundred and four parents enrolled in the study, and SCCC data at study enrollment were available for 86 parents (83%). Responding parents were predominantly white, non-Hispanic/Latina women with greater than high school-level education (see Table 1). Child age, duration of advanced cancer at time of study enrollment, and proportion of each cancer type were comparable among SCCC respondents and non-respondents.

Over the preceding 3 months, 63% (n=54) of parents reported excellent TDC. Involvement in care was universal for oncologists and nearly universal for clinic-based primary nurses. Involvement in care was more variable for hospital-based primary nurses and psychosocial clinicians, with 29% of parents (n=23, n=24) indicating no involvement for each of these clinician types (see Table 2). However, parents indicated all children had at least one primary nurse, based either in the hospital or clinic (n=85, 1 missing response). Among those parents who indicated involvement, seventy-six percent (n=65) reported excellent care from the primary oncologist, 68% (n=55) reported excellent quality of care from an outpatient

primary clinic nurse, 72% (n=41) reported excellent care from a hospital primary nurse, and 43% (n=26) reported excellent care from a psychosocial clinician. Slightly less than half of parents reported excellent teamwork between the various healthcare professionals involved in their child's care (47%, n=40), and 26% (n=22) reported receiving conflicting information sometimes/often (see Table 2).

Table 3 shows associations between candidate factors and excellent TDC. Reports of excellent TDC ranged from 54% among parents of children with advanced hematologic malignancies to 65% among parents of children with advanced extra-cranial solid tumors and 78% among parents of children with advanced CNS tumors. Seventy-one parents perceived low suffering among their children and 14 perceived high suffering. More parents who perceived low suffering among their children reported excellent TDC (n=47, 66%) than did parents who perceived high suffering (n=6, 43%), though in this relatively modest sample, these apparent differences in point estimates by disease type and perceived degree of suffering were not statistically significant. For each clinician type, excellent care provided by the individual clinician was associated with parent perceptions of excellent TDC (p = 0.001 each clinician type, no adjustment for multiple comparisons). As anticipated, parent perceptions of the care team working together excellently and rarely/never receiving conflicting information were each significantly associated with reporting excellent TDC (working together: p<0.001; information receipt: p=0.02). Given the relatively high percentage of parents reporting no psychosocial clinician involvement in their child's care (29%, see Table 2), we also examined whether involvement of a psychosocial clinician was associated with excellent TDC. Seventy-five percent of parents who indicated no psychosocial clinician involvement reported excellent TDC, while 60% of parents who reported psychosocial clinician involvement in their child's care reported excellent TDC (p=0.22). Among those parents who reported less-than-excellent-teamwork, only 35% reported that their child received excellent TDC over the preceding 3 months (see Table 3). Parent characteristics, including gender, race, ethnicity, and educational attainment were not associated with parent perceptions of TDC, though our ability to detect potential small differences was limited due to modest sample size.

Discussion:

This cross-sectional survey of parents of children with advanced cancer found that more than one-third reported less-than-excellent TDC over the preceding 3 months. Additionally, less than half reported excellent teamwork, and ratings of care rendered by individual clinicians were highly variable. These findings are particularly striking given that this study was conducted at three large, well-resourced children's cancer centers.

Modern pediatric cancer care is founded on the notion that multiple forms of expertise arising from multiple individuals inhabiting different roles are required to deliver high-quality care.²⁰ As such, it is not a question as to whether we should form teams to achieve our aims, rather how to ensure that our teams perform excellently. Relatively little is known about how parents conceptualize TDC in advanced cancer, including which aspects of TDC are most visible and deemed most important. Our results suggest that parents see both care rendered by their child's individual clinicians and teamwork as highly salient components of

TDC. Specifically, nearly all parents who reported excellent care by their child's oncologist also reported excellent TDC, and similarly, most parents who described the teamwork between their child's clinicians as excellent reported excellent TDC. At the same time, almost one-fifth of parents who reported that the care delivered by the oncologist was excellent reported less-than-excellent TDC, supporting the notion that TDC requires more than the efforts of one clinician. Furthermore, receipt of conflicting information was inversely associated with excellent TDC. Fostering excellent TDC may be particularly important in the setting of advanced cancer, as many children with advanced cancer will die of their disease, and many will interact with the healthcare system for years.³ Importantly, bereaved parents who perceive that their child received excellent care may have superior outcomes to those who have regrets about the care their child received.^{21,22}

These cross-sectional data have important limitations. Parent respondents were over-represented for white women who were highly educated. Their perceptions may have limited generalizability to more diverse populations of family caregivers.²³ Furthermore, the survey did not query involvement by other clinicians such as radiation oncologists, surgeons, other pediatric subspecialists (e.g. palliative care, critical care, infectious disease), child life specialists, and physical or occupational therapists, who are commonly involved in the care of children with advanced cancer and whose contributions may also affect parent perceptions of TDC. Additionally, the extent to which parents focused on the "team" aspect of TDC when responding to the survey cannot be determined from these data. However, the finding that fewer parents rated TDC as excellent in comparison to care ratings selected for individual clinicians such as the oncologist and primary nurse suggests that parent respondents took into account multiple contributions to their child's care when answering about TDC quality. Most importantly, in the setting of a modest sample size, we did not construct more complex multivariable models incorporating multiple clinician types and interaction terms, as would be necessary to more systematically investigate the independent contributions of factors that appear to be associated with parent perceptions of excellent TDC, and we lacked statistical power to confirm potential differences in perceived TDC quality among parents who perceived high versus low child symptom suffering.

Despite these limitations, our findings suggest that interprofessional teamwork in the care of children with advanced cancer is perceived to be highly variable by their parents, thus falling short of the Triple Aim to achieve high quality healthcare for these children. Theories of teamwork suggest both profound benefits and potential pitfalls, including the possibility for synergy—better care than any individual could deliver solely—and potential for getting bogged down—so-called collaborative inertia.²⁴ This study suggests interventions are needed to enhance interprofessional teamwork in the care of children with advanced cancer.

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Abbreviations:

CNS	Central nervous system
CHOP	Children's Hospital of Philadelphia
CI	Confidence Interval
DF/CH	Dana-Farber and Boston Children's Cancer and Blood Disorders Center
IQR	interquartile range
OR	Odds Ratio
PediQUEST	Pediatric Quality of Life and Evaluation of Symptoms Technology
SCH	Seattle Children's Hospital
SD	Standard Deviation
SCCC	Survey about Caring for Children with Cancer
TDC	Team-Delivered Care

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Table 1:

Parent and child characteristics

	N (%) ^a or Median (range)
Parents (n=86)	
Age at enrollment, years (n=85)	43.9 (22.1–65)
Female gender	74 (86)
Race (categories are not mutually exclusive, n=82)	
American Indian/Alaskan Native	2 (2)
Asian	1 (1)
Black or African American	5 (6)
Native Hawaiian or Other Pacific Islander	0 (0)
White	76 (93)
Other	2 (2)
Race (n=82)	
White only	74 (90)
Ethnicity (n=83)	
Hispanic or Latino	6 (7)
Educational Attainment	
Greater than high school education	56 (65)
Children (n=86)	
Age at enrollment, years ^b	12.1 (2.1–22.5)
Female gender	46 (53)
Cancer type	
CNS tumor	9 (10)
Hematologic malignancy	28 (33)
Non-CNS solid tumor	49 (57)
Healthcare site	
CHOP	21 (24)
DF/BCH	49 (57)
SCH	16 (19)

CNS = Central nervous system; CHOP = Children's Hospital of Philadelphia; DF/BCH = Dana-Farber and Boston Children's Cancer and Blood Disorders Center; SCH = Seattle Children's Hospital; SD = Standard Deviation;

^aDenominator N=86 unless otherwise specified; percentages may not add to 100 due to rounding;

^bDetermined at study entry; for some participants, there was a delay between date of entry and date of survey completion

Table 2:

Parent report of team-delivered care quality, clinician involvement, clinician care quality, teamwork, and communication in last 3 months

	N ^a (%)
Team Delivered Care (TDC) (n=86)	
Excellent	54 (63%)
Less-than-excellent	32 (37%)
Care from primary oncologist (n=86)	
Not involved	0 (0%)
Involved	86 (100%)
Excellent	65 (76%)
Less-than-excellent	21 (24%)
Care from hospital primary nurse (n=80)	
Not involved	23 (29%)
Involved	57 (71%)
Excellent	41 (72%)
Less-than-excellent	16 (28%)
Care from outpatient clinic primary nurse (n=84)	
Not involved	3 (4%)
Involved	81 (96%)
Excellent	55 (68%)
Less-than-excellent	26 (32%)
Care from child's psychologist/social worker (n=84)	
Not involved	24 (29%)
Involved	60 (71%)
Excellent	26 (43%)
Less-than-excellent	34 (57%)
Healthcare teamwork (n=86)	
Excellent	40 (47%)
Less-than-excellent	46 (53%)
Frequency of receiving conflicting information from different members of care team (n=86)	
Rarely/never	64 (74%)
Often/Sometimes	22 (26%)

^a Percentages may not add to 100 due to rounding

Table 3:

Factors potentially associated with parent report of excellent team-delivered care (TDC) quality in last 3 months

Factor of Interest	Category	Proportion Reporting Excellent Team-Delivered Care	N ^a	p-value ^b
Type of advanced cancer	CNS tumor	0.78	86	0.37
	Hematologic malignancy	0.54		
	Non-CNS solid tumor	0.65		
Perceived suffering from child's symptoms	Low suffering	0.66	85	0.13
	High suffering	0.43		
Care from child's oncologist	Excellent	0.82	86	<0.001
	Less-than-excellent	0.05		
Care from child's primary hospital nurse	Excellent	0.80	57 ^c	0.001
	Less-than-excellent	0.31		
Care from child's outpatient clinic primary nurse	Excellent	0.80	81	<0.001
	Less-than-excellent	0.38		
Care from child's psychologist/social worker	Excellent	0.88	60 ^c	<0.001
	Less-than-excellent	0.38		
Child's caregivers working together as a team	Excellent	0.95	86	<0.001
	Less-than-excellent	0.35		
Frequency of receiving conflicting information from different members of care team	Rarely/Never	0.70	86	0.02
	Often/Sometimes	0.41		
Gender	Female	0.65	86	0.35
	Male	0.50		
Race	Persons of Color ^d	0.63	82	1.00
	White	0.62		
Ethnicity	Hispanic or Latino	0.83	83	0.41
	Non-Hispanic	0.62		
Education	More than high school education	0.66	86	0.48
	High school education or less	0.57		

Abbreviations: N/A not applicable;

^aNumber of observations;

^bFisher's exact test, p-values not adjusted for multiple comparisons;

^cLow numbers reflect n>20 parents who reported this clinician type was uninvolved in child's care (see also Table 2);

^dTwo individuals who self-identified as multiple races, including white, were classified in each self-identified racial category indicated in Table 1. Given a modest sample, race was dichotomized for the analysis shown above. These two individuals were included in the "Persons of Color" category. See Table 1 for more granular self-reported race data.