

Feasibility, Acceptability, and Usability of Web-Based Data Collection in Parents of Children With Cancer

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Childhood cancer is rare, affecting about 10,400 children 15 years and younger each year in the United States (National Cancer Institute, 2008). As a result, collaborative multisite studies are necessary to ensure adequate sample sizes of pediatric patients for disease-directed and cancer-control studies. Within the Children's Oncology Group, the nursing discipline has made great strides in bringing nursing research expertise into the cooperative group mechanism to systematically study the responses of children and families to cancer and its treatment (Ruccione, Hinds, Wallace, & Kelly, 2005). These types of studies typically include complex self-report instruments that require time for participants to complete, as well as expensive and extensive data entry. Novel methods for data collection and management are needed to facilitate future nursing research within the cooperative group structure.

Internet technologies increasingly are being applied to health outcomes and psychological research. Establishing Web-based electronic portals where study participants can complete self-report questionnaires has become common (Cronk & West, 2002). The application of innovative Internet technologies for data collection and intervention delivery, such as treatment decision-making research, holds considerable promise for facilitating an even broader range of behavior studies to improve outcomes for children with cancer and their families (Burns, Robb, & Haase, 2009).

Literature Review

To the extent that researchers have directly compared Web-based to paper-and-pencil data collection, measurement properties have been reported to be comparable or even improved with Web-based instruments (Bliven, Kaufman, & Spertus, 2001; Cronk & West, 2002; Gwaltney, Shields, & Shiffman, 2008; Pettit, 2002; Truell, Bartlett, & Alexander, 2002). No significant dif-

Purpose/Objectives: To determine the feasibility of Web-based, multisite data collection using electronic instruments and the feasibility, acceptability, and usability of that data collection method to parents of children with cancer.

Design: Prototype development and feasibility study.

Setting: Three Children's Oncology Group centers in the United States.

Sample: 20 parents of children with cancer who made a treatment decision within the previous six months.

Methods: Eight instruments were translated from print to electronic format and deployed using a secure Web-based server. Parents completed printed versions of two of the instruments to assess comparability of the two formats. A post-survey interview focused on parents' computer experiences and the acceptability and ease of use of the instruments.

Main Research Variables: Time to orient parent to Web site, time to complete instruments, investigators' field notes, and postsurvey questionnaire.

Findings: Eighty percent of parents preferred the Web-based data collection and found it at least as easy as completing paper-and-pencil instruments. All parents, regardless of their computer expertise, were comfortable with the electronic data collection system. Statistical analysis demonstrated no evidence of systematic or clinically significant bias.

Conclusions: The Web-based data collection was feasible, reliable, and preferred by most study participants. The authors will use this strategy in future intervention trials of parents making treatment decisions.

Implications for Nursing: Web-based data entry is feasible and acceptable to parents of children with cancer. Future multicenter collaborative studies should develop and test nursing interventions to support parents making treatment decisions.

ferences have been observed in item variance or mean scores (Bliven et al., 2001; Cronk & West, 2002), scale completion rates (Bliven et al., 2001; Truell et al., 2002), response set biases (Pettit, 2002), or psychometric properties (Bliven et al., 2001; Pasveer & Ellard, 1998; Vispoel, Boo, & Bleiler, 2001). Krantz and Dalal (2000) reviewed

research on the validity of Web-based studies, stating, "In all cases, there seems to be a surprising match between laboratory and Web versions of surveys, scales, and experimental variables" (p. 56). Krantz and Dalal (2000) went on to state that Web-based and paper-and-pencil research from the same study yielded results that "essentially replace each other" (p. 56). In several direct comparison studies, participants expressed a preference for Web-based data collection over paper-and-pencil methods (Bliven et al., 2001; Vispoel et al., 2001).

Despite positive appraisals of Web-based data collection, issues related to data quality may arise when researchers do not have direct access to participants. Issues identified in earlier Web-based studies include participants taking surveys more than once, false or missing data, and surveys being distributed to and completed by individuals outside the target population (i.e., people e-mailing survey links to friends or posting the links on Web sites) (Birnbaum, 2004; Cantrell & Lupinacci, 2007). Advances in security technologies have offered more researcher control over participant access and participation, allowing the use of electronic communication for virtually every aspect of research implementation, including obtaining consent, randomizing intervention participants, and transmitting highly sensitive personal information. Clinical trials with Web-based interventions have been performed successfully with teenagers and adults (Hester, Delaney, Campbell, & Handmaker, 2009; Van Voorhees et al., 2009).

Although Internet usage is commonplace in many U.S. households, reliance on Web-based technology could limit study samples to those with experience and comfort using electronic communication, leading to biased study findings. However, when study entry procedures and instruments are kept simple, user satisfaction with electronic data collection remains high, even for participants with low literacy and little computer experience (Bliven et al., 2001).

Costs for electronic data collection are highest at start-up, with the majority of expenses related to creation of the user interface and the hardware and software systems that support secure transmission of data. Minimal incremental costs exist for additional sites or participants because data management tasks such as data entry, cleaning, and construction of scale scores are automated; overall project costs typically are comparable to or even less than conventional research methods (Weber, Yarandi, Rowe, & Weber, 2005). Other benefits of Web-based data entry by the participant are a lower likelihood of data transcription errors and the ability to include response checking to prevent participants from submitting answers with illogical or missing data (Ahern, 2005).

Nursing researchers who have reported their experiences with Web-based research methods recount the inevitable difficulties discovered in the implementation

phase, including software incompatibilities and barriers to participation within the clinical setting (Berry et al., 2004, 2006; De Leo et al., 2005; Mullen, Berry, & Zierler, 2004). These issues highlight the importance of beta testing in the development phase.

The current highly competitive funding climate mandates that nursing studies demonstrate efficient and cost-effective multisite mechanisms to achieve high-priority research goals (Reaman, 2004). The use of Web-based technologies within the cooperative group infrastructure offers considerable promise for yielding high-quality data from representative samples and thereby advancing a nursing research agenda. The authors did not find any studies that described systems for Web-based data collection in parents coping with the stress of caring for a child with cancer. Demonstrating the feasibility of Web-based data collection in a parent population that experiences high emotional distress and often is unable or unwilling to leave the child's bedside to complete study procedures is important. Therefore, the purpose of the current study was to determine the feasibility of multisite data collection using electronic instruments accessed via an interactive Web site and to determine the feasibility, acceptability, and usability of that data collection method to parents of children with cancer.

Methods

Design

The authors combined quantitative and qualitative methods to evaluate the feasibility, acceptability, and usability of procedures to implement electronic data collection. Feasibility was evaluated by the successful deployment of the computer program, successful completion of the surveys by parents, and number of refusals to participate. Acceptability was assessed by qualitative analyses of parent responses to a brief, post-survey interview about their experiences completing the Web-based survey and the paper-and-pencil surveys. The evaluation of usability was based on qualitative analyses of user feedback regarding ease of navigation and use and the time required to complete the data collection procedures.

Development of the Web-Based Survey

Survey platform: The hardware and software systems to support Web portal access, data collection, and management were developed in collaboration with the University of Missouri Assessment Resource Center. Paper-and-pencil instruments were converted to HTML files that appeared as Web pages hosted on a dedicated Web server. The survey was written using ASP.NET Web page-making language, and the Web site was hosted

through Microsoft's Internet Information Services for Windows®. The software was run on a set of Dell™ PowerEdge™ servers, mirrored for redundancy, that were backed up daily.

Security was established and maintained by means of multiple layers of firewall protection and high-level encryption during data transmission. Access to the Web portal required a valid, unique user name and password. In developing and deploying a process to be performed at distant sites, the authors emphasized server-side computing so as to be independent of significant processing by local client machines. In that way, the study would be least likely to be affected by differences in software, hardware, operating systems, or updates or service packs of the browser used (Berry et al., 2004).

Content development: The principal investigator met with the Web developers to create a prototype interface based on the research team's initial design. Subsequent consultations with the research team led to alterations and improvements in the appearance and functionality of the interface, including overall graphic design and appearance, consistency of the interface (e.g., study logo in a corner of each page), a countdown to completion (i.e., an indication of the number of pages completed and remaining on each page), clarity of instructions, and an increased number of questions on each page. A key design feature was that the participant could not advance to subsequent pages unless all questions were completed. Two of the study instruments, the Control Preferences Scale–Pediatrics (CPS-P) and the Information Needs Questionnaire (INQ) used complex response formats that required careful adaptation to the electronic environment (see Table 1). After multiple iterations, the investigators were satisfied with the prototype and the project moved to the implementation phase.

Survey deployment: A coding manual reflecting the record layout was developed and verified. The authors confirmed accuracy of the Web-based data entry by logging in using practice passwords, entering sample data, and cross-checking the entered data with the record layout output. The estimated time for survey development was two months, but the phase actually took about eight months.

Once the survey was deployed at the investigators' institutions, minor unanticipated problems with functionality were noted with initial study entries. For example, at one institution, the standard institutional

personal computer software version would cache a copy of a survey page. When an attempt was made later to access the survey from the same computer, the user would be presented with an old version of the page. The solution was to clear the Web browser cache prior to a session. At another institution, a parent noticed pop-up advertisements during the Web survey, which subsequently were disabled. Server access occasionally was a problem because of routine maintenance or, in one instance, because of a computer virus. A commercial Web-blocking program was installed at one institution midstudy that blocked access until the study servers were added to the list of safe sites.

After these issues were resolved, most parents were able to complete the survey without difficulty. Several interviews were completed using a laptop computer with wireless Internet access. A few parents were interrupted by clinicians or other demands during completion

Table 1. Internal Consistency of Study Instruments (Electronic Versions)

Variable	Instrument	Total Items	Cronbach Alpha	
			Reported	Study
Contextual				
Severity of illness	Severity of Illness Scale (adapted) (Young-Saleme & Prevatt, 2001)	6	0.79–0.8	0.7
Trust in physician	Trust in Physician Scale (Anderson & Dedrick, 1990; Thom et al., 1999)	11	0.85–0.9	0.76
Uncertainty	Parent Perception of Uncertainty Scale (Mishel, 1983)	32	0.86–0.93	0.71
Process				
Information priorities	Information Needs Questionnaire (Pyke-Grimm et al., 1999)	36	0.69 ^a	0.7 ^a
Treatment decision-making role	Control Preferences Scale for Pediatrics (Pyke-Grimm et al., 1999)	5	52%–59% ^b	Sample size too small
Outcome				
Decisional conflict	Decisional Conflict Scale (O'Connor, 1997)	16	0.78–0.92	0.73
Satisfaction with decision	Satisfaction With Decision Scale (Holmes-Rovner et al., 1996)	6	0.86–0.88	0.79
Satisfaction with information	Satisfaction With Information Scale (Kelly et al., 2007)	9	–	0.77

^a Gulliksen and Tukey's index of reliability

^b Coombs' reliability criterion

of the survey but were able to return to the survey where they left off. After an extensive period of development and testing, the Web-based technology was deployed and used successfully by parents.

Sample and Setting

The study was conducted with a convenience sample of 20 parents of children with cancer at three university-affiliated regional pediatric cancer centers in the United States—two moderate-to-large centers on the West Coast ($n = 10$) and in the Mid-Atlantic ($n = 7$), and one small center in the Midwest ($n = 3$). A sample size of 20 produces a 95% confidence interval for the proportion of parents who prefer Web-based data collection equal to the sample proportion ± 0.20001 when the estimated proportion is 0.5. Inclusion criteria were parents of children age 12 or younger who were undergoing treatment for cancer who had made a decision about whether their child would participate in a phase II or III clinical trial within the past six months. The sample was limited to parents of preadolescent children to focus on responsibility for surrogate decision making (Olechnowicz, Eder, Simon, Zyzanski, & Kodish, 2002). Any custodial parent or guardian who had primary or shared responsibility for the care of the child was eligible to participate. When both parents were willing to participate, the authors randomly selected one parent. As the complete set of study instruments were available only in English versions, parents were excluded if they self-identified as non-English speaking. Parents who chose not to participate were asked to describe their reasons for refusing.

Procedures

After institutional review board approval was obtained at each site, potential participants were identified and approached by treatment team members to determine their willingness to meet with the site investigator. The site investigators maintained frequent contact with clinical staff during data collection to facilitate participant referral. The investigator met with interested parents, explained the study, obtained informed consent, and coordinated data collection. Study procedures, including parent interviews, were conducted in outpatient or inpatient areas, depending on parents' preferences, schedules, and room availability.

The investigator oriented parents to the Web site and explained procedures for completing the electronic and paper-and-pencil questionnaires. Once parents were comfortable with the procedures, the investigator provided privacy while remaining available for assistance. Data from each submission were saved on a secured server. Participants were identified in the database only by their study identification number, which was linked to their name only at the local institution and kept in a secured, locked location.

The investigator documented the time needed to orient parents to the computer, log into the program, and to complete the electronic studies. Following completion of the study questionnaires, parents were interviewed by the on-site investigator to evaluate their overall experience using the electronic data collection system, frequency of computers use, and comfort with the technology.

Instruments

Selection of the instruments for electronic data collection was based on the authors' evolving conceptual model of parental treatment decision making (Stewart, Pyke-Grimm, & Kelly, 2005). In addition to brief demographic and disease questions, eight established self-report instruments, representing elements of the conceptual model, were converted identically into the electronic format.

To confirm the comparability of electronic and printed instruments in this population (Gwaltney et al., 2008), parents were asked to complete two of the instruments—the Severity of Illness Scale (SOIS) (Young-Saleme & Prevatt, 2001) and the Satisfaction With Decision Scale (SWDS) (Holmes-Rovner et al., 1996)—in printed format. The order of electronic or paper-and-pencil administration was assigned randomly. These instruments were selected because they were converted most easily. Only two of the eight instruments were administered both ways to reduce responder burden.

Data Analysis

Descriptive statistics were calculated for each instrument and version (electronic versus paper-and-pencil). Bland and Altman (1986) plots were used to examine the difference in the paper-and-pencil and electronic scores, the distribution of the differences, and whether the differences were related to the magnitude of the measurement. These plots are used to examine agreement between two methods of measurement by plotting their differences on the y-axis versus their mean on the x-axis. Normality was examined using histograms and formally tested using the Shapiro-Wilk test to verify the null hypothesis that the sample was from a normally distributed population. The only instrument found to violate the normality assumption was the SWDS. The INQ was analyzed for reliability using Gulliksen and Tukey's (1958) analysis of variance. The CPS-P was not analyzed using Coombs' (1964) criterion for reliability because of the limited sample. The Satisfaction with Information Scale was pilot tested in the current study. The Satisfaction with Information Scale is a nine-item, four-point Likert-type scale (i.e., very satisfied to not at all) that measures parents' satisfaction with the pediatric cancer information they have received.

To examine the order effect, the mean differences in the two scores (paper-and-pencil or Web-based) were compared between parents who completed the electronic method first and those who completed the paper-and-pencil method first using a Mann-Whitney test. Comparison of means for the electronic and paper-and-pencil collection methods were conducted using a Wilcoxon signed-ranks test. A significant difference in the mean scores for the electronic and paper collection methods would indicate evidence of a systematic bias. The weighted kappa coefficient was used to examine individual agreement between the two data collection methods; coefficients close to 1 indicate stronger agreement (Landis & Koch, 1977).

The Web-based method was considered acceptable if more than 50% of the parents preferred it to the paper instrument or had no preference. The percentage of parents who preferred the Web-based method or had no preference was summarized using a 95% CI. A convenience sample of 20 participants was determined to provide sufficient experience to determine the feasibility of the Web-based electronic data collection as well as identify any changes needed in the data collection process.

Interviews with parents about their overall experience using the electronic data collection system were reviewed to identify problems with implementation and factors that might influence the validity of a subsequent groupwide study. The investigators asked four ordinal-level questions to determine the parents' frequency of computer use and ease of use of the Web-based program, as well as seven open-ended questions to obtain additional feedback about the program itself. Field notes from the interview were subjected to content analysis.

Results

Sample

Twenty parents (16 mothers and 4 fathers) participated in the study (see Table 2). The affected children averaged 4.7 years old and 75% were male. The most common diagnosis was acute lymphoblastic leukemia ($n = 14$), followed by neuroblastoma ($n = 3$), acute myelogenous leukemia ($n = 1$), non-Hodgkin lymphoma ($n = 1$), and histiocytosis ($n = 1$). Mean time from diagnosis was 2 months ($SD = 1.6$), with a median of 1.4 months and a range of 0.2–5.3 months.

Three parents declined to participate. One parent was too busy, one was not comfortable using a computer, and one who initially agreed to participate eventually declined without explanation.

No evidence of order effect existed between the SOIS ($p = 0.28$) and the SWDS ($p = 0.63$). The mean difference between the two modes was less than one unit for

Table 2. Participant Characteristics

Characteristic	$\bar{X}$	SD
Age (years)	34.5	7.8
Characteristic	n	
Gender		
Female		16
Male		4
Race		
Caucasian, non-Hispanic		16
Black, non-Hispanic		1
Hispanic or Latino		1
Asian or Pacific Islander		1
Other		1
Education		
Less than high school		1
High school diploma		5
1–2 years of college		3
College diploma		7
Postgraduate degree		4
Marital status		
Married		17
Common-law marriage or living together		1
Separated		1
Divorced		1
N = 20		

the SOIS and SWDS summary scores. The mean score of the SWDS was not significantly different between the Web-based and paper-and-pencil methods ($\bar{X} = 26.65$, $SD = 2.76$ versus $\bar{X} = 26.9$, $SD = 2.67$, $p = 0.37$). SOIS scores from the Web-based instrument differed significantly from those obtained using paper and pencil ($\bar{X} = 22.2$, $SD = 4.58$ versus $\bar{X} = 23.15$, $SD = 3.96$, $p = 0.03$). However, the magnitude of the mean difference (one point out of a possible total of 42) is unlikely to represent a meaningful difference.

The weighted kappa coefficients for individual agreement between the paper-and-pencil and the Web-based data were 0.75 for the SOIS and 0.78 for the SWDS, indicating good to very good agreement. Individual questions from each scale also showed good to very good agreement, with weighted kappa coefficients all more than 0.63. Bland and Altman plots for the SOIS and SWDS summary scores revealed no evidence of systematic bias.

Acceptability and Usability of the Web-Based Format

Eighty percent of parent participants ($n = 16$) preferred the Web-based format over paper-and-pencil, 15% preferred the paper-and-pencil format ($n = 3$), and 5% ($n = 1$) expressed no preference. In total, 85% (95% CI = 69%–99%) ($n = 17$) preferred the Web-based format or had no preference, strongly supporting its acceptability. Seventy-five percent of parent participants ($n = 15$)

were very comfortable and 25% (n = 5) were somewhat comfortable with the Web-based format.

The time required to orient the parents to the Web-based survey averaged 2.8 minutes (median = 2 minutes, range = 1–10 minutes). Parents completed the Web-based survey in an average of 28.3 minutes (median = 27, range = 15–45 minutes).

Postsurvey interview responses: Eighty-one percent of the 16 parents who preferred the Web-based format (n = 13) reported one or more hours of computer use per week, with 69% (n = 11) reporting daily computer use. Three parents who preferred the paper-and-pencil format reported that they used a computer almost never. The parent who had no preference for either method used a computer every day. About 63% of the parents who preferred the Web-based format found it easier or much easier (n = 10). Parents who preferred the paper-and-pencil format also found the Web-based format easier (n = 1) or about the same (n = 2).

Parents' comments demonstrated that, for many, the formats essentially were the same and they were comfortable with both. They recognized that the format was similar (e.g., "You mark a bubble either way."), both survey formats read the same, and comprehension was equivalent. Positive comments included enjoying computer use and liking the prompts to move to the next screen. One parent commented that it was "more natural than writing." Parents found the program convenient, easy, and quick compared to the paper-and-pencil format (e.g., "Speed is priority." "It seemed to go faster than paper-and-pencil."). Specific benefits of the Web-based format included, "You know how many questions are remaining," and "You don't miss questions." Parents appreciated the ability to navigate through the survey and change answers without flipping pages.

Twelve parents made negative comments, most of which pertained to the content rather than the format of the questionnaires. All twelve parents commented on the repetitive nature of the two scales (CPS-P and INQ), which both used a paired comparison approach format. Two parents complained about the wording of items or response choices (e.g., double negatives, difficulty interpreting scale anchors), and three reported difficulties using the mouse. One parent preferred the paper-and-pencil method because it was more portable, ensuring it could be completed at the child's bedside.

In response to the request for recommendations for improving the survey, parents offered several helpful comments. Suggestions regarding page design included more clear labeling, brief survey instructions, more questions per page to shorten overall length, reduced scrolling requirements, and increasing the font size. One parent asked for the ability to write in additional comments to explain answers.

Discussion

The authors successfully deployed a Web-based, multisite data collection system in a clinical pediatric oncology environment using instruments accessed via an interactive electronic portal. Minor software problems were overcome, and the portal was accessible and functional within three institutions' information technology infrastructures. Although unanticipated issues lengthened the time line to deployment and completion, the methodology proved very feasible and highly acceptable to parent participants.

The threshold criterion for acceptability by 50% of parents was exceeded, with 80% of parents preferring the Web-based format to paper-and-pencil instruments. Parents who preferred the paper-and-pencil format largely acknowledged that they were comfortable with the Web-based format. Most parents found Web-based data collection at least as easy as completing paper-and-pencil instruments, with added convenience and speed.

These results mirror findings in other populations, such as adult patients receiving radiotherapy for cancer (Mullen et al., 2004) or user satisfaction with computerized data collection in a broad range of adult patients with cancer (Wolpin et al., 2008). The current study contributes to the accumulating evidence that Web-based data collection not only is feasible but may become the preferred method of data collection.

Parents' comments confirmed their preference for Web-based versus paper-and-pencil formats and also contributed valuable insights about improvements that could enhance the acceptability and usability of the Web-based format. Minor problems with using the computer mouse suggested that touch screen devices could be a viable alternative for data collection. Providing access to laptop computers for data collection at the bedside or developing training materials that support parents' accessing the portal and entering data from their home computer could enhance study participation by parents who are unable or reluctant to leave their child's side in the treatment environment.

Although start-up costs for electronic portal development and deployment are higher than those associated with traditional data collection methods, the costs easily would be offset by reduced personnel costs in a large-scale study. One study suggested the break-even point was as low as 32 patients (Weber et al., 2005). Participants entering data directly via the electronic portal avoid the typical 8.5% transcription error rate (Weber et al., 2005) that must be addressed with verification and cleaning of written responses. Prompts for missing or illogical responses can be built into electronic platforms to reduce the need for data review and improve data quality. These advantages are magnified for multisite studies, which generally require extensive procedural attention for data consistency and integrity.

The authors did not detect meaningful differences between electronic and paper-and-pencil versions of two of the instruments used in the current study, which is consistent with Gwaltney et al.'s (2008) meta-analysis of instrument comparability. In studying about 300 comparisons between paper-and-pencil and computerized psychological questionnaires, the authors of that study concluded that equivalence testing typically is not necessary when transferring an assessment from paper to computer; they found uniformly high correlations. Gwaltney et al. (2008) concluded that paper-and-pencil and computerized measures result in equivalent scores.

Limitations

Limitations existed in the current study. The small, three-institution sample was relatively homogenous and made up mostly of Caucasian, English-speaking mothers who were well educated and used computers on a regular basis. Study findings may not be generalizable to the broader population of parents of children with cancer. Surprisingly, only one parent refused to participate because of discomfort with computer use. Other researchers have similarly reported satisfaction with electronic data collection from participants with little computer experience (Bliven et al., 2001).

Conclusion and Implications for Nursing

The data generated from the current study indicate that Web-based methods are a highly acceptable, feasible, and even preferable means of gathering information. The main implication of these results is that electronic data collection is well accepted by a select sample of parents, including some who reported infrequent computer use. Given the high acceptance of the Web-based program, the equivalence of paper-and-pencil and computerized questionnaires, and the cost-effectiveness and improved data quality with

Internet-facilitated data collection methods, such systems can be employed confidently in large-scale, multisite studies of psychosocial issues relevant to pediatric oncology nursing research.

The informative parent feedback from the current study will be used to refine the authors' Web-based data collection system for use in future multisite trials to test interventions designed to support parental treatment decision making within the Children's Oncology Group environment. The current study will serve as the prototype for an expanded research program that supports linkages to intervention materials to improve parent-provider communication and psychological outcomes for families facing stressful and life-altering decisions about cancer treatment.

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