

Parent satisfaction with education, support, and decision-making regarding their children's central venous access devices

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Abstract

This descriptive, exploratory study assessed parents' satisfaction with the education and support they received before and after their children had central venous access devices (CVADs) inserted for cancer treatment. Decisions regarding the type of CVAD and parent satisfaction with that choice were also evaluated. Parents of children who experienced a CVAD during the six-year period 1992-1997 participated. Data were collected through telephone interviews using a questionnaire specifically designed for the purposes of the study. Results suggest that parents were satisfied with the teaching and support received both prior to and following CVAD insertion. Other findings reveal that not all parents take part in decisions about the type of device used, and that if given a choice, based on their experience, they would likely choose implanted ports over Hickman® catheters.

Central venous access devices (CVADs) are frequently used in the treatment of pediatric oncology patients. These devices allow for better treatment management during medical procedures and less trauma for children undergoing treatments (Keegan-Wells & Stewart, 1992). Two major types of CVADs currently in use are Hickman® catheters (Bard Access Systems, Salt Lake City, UT) and totally implantable ports (implanted ports).

These two devices are the ones most commonly used at the major child health centre in the province of Newfoundland and Labrador. At this centre, following a child's initial diagnosis of cancer, parents are usually informed about the two types of CVADs and the advantages and disadvantages of each. It is not known, however, if the information given is sufficient or presented in the best way during this highly stressful period. Also at this time, parents may have input into the decision as to which type of device is chosen for their child. No information is available about the parents' contribution to this decision nor whether they are satisfied with the choice.

Following the insertion of the CVAD, parents are offered an educational and support program so that the children can return home between treatments. To date, no research has been done to assess parents' satisfaction with this program nor to determine if parents feel adequately prepared to care for their children between treatments.

Literature review

Much has been written on the subject of central venous access devices. The majority of these writings are clinical research papers that analyze and discuss the various benefits and complications associated with the use of external and/or totally implantable catheters (Becton, Kletzel, Golladay, Hathaway, & Berry, 1988; Brincker & Saeter, 1986; Brothers et al., 1988; Dawson et al., 1991; DeBacker, Vanhulle, Otten, & Deconinck, 1993; Gyves et al., 1982; Jolley, 1995; Wacker et al., 1992; Wiener et al., 1992). One recent research article by Dearborn and colleagues (Dearborn, De Muth, Requarth, & Ward,

1997) linked adult patients' and nurses' satisfaction with three types of CVADs to various benefits and problems associated with them. There are also some clinical discussion papers, written from medical or nursing perspectives, which outline the history, uses, benefits, and disadvantages of the various types of CVADs (Iannacci & Piomelli, 1984; Keegan-Wells & Stewart, 1992; Wesley, 1992).

The literature provides no information regarding parents' satisfaction with the choice of CVAD. Also lacking is any evidence of research to evaluate parent education or support programs related to the types of devices or their post-surgical care and maintenance. Akcasu and Bodenmiller (1994) did discuss the development of a parent education video on the care of CVADs, but made no reference to any attempts to evaluate its effectiveness.

The purposes of this study were to conduct an evaluation of the CVAD education and support program that currently exists at a major provincial child health centre, and to determine if parents were satisfied with the care provided to them and their children. The following questions were addressed:

1. Are parents of children with cancer being fully informed about central venous access devices prior to surgical insertion of these devices?
2. Are these parents satisfied with the pre-surgical teaching they received regarding CVADs?
3. Do parents have input into the decision related to CVAD choice?
4. Do the parents experience immediate and/or long-term satisfaction with the type of device that was inserted?
5. Is there a difference in satisfaction between parents of children who experienced Hickman's and those who experienced implanted ports? and
6. Are parents satisfied with the teaching and support they received from health professionals regarding the care of their child's CVAD?

Methods

This descriptive survey was based on a convenience sample that included one of the parents of each child who had a CVAD inserted and who underwent cancer treatment at the main child health centre in Newfoundland between 1992 and 1997. On the recommendation of the organization that funded the study, the parents of children who had died were excluded in order to avoid causing them unnecessary distress. (The original intention was to include them in the study, a plan that had been supported by the members of the local human investigation ethical review committee who had granted approval for the project). All of the 50 parents remaining in the sample were included in the survey.

The parents were first contacted by letter to inform them about the study, to ask for their participation, and to tell them that a research assistant would telephone them in the near future. They were also advised that they could refuse participation by contacting one of the researchers beforehand or by telling the research assistant at the time of telephone contact.

The instrument was specifically designed for this investigation. It consisted of 83 questions which were developed after a literature review and in collaboration with the child health centre's oncology nurse coordinator. An expert nurse from the oncology unit and a nurse researcher reviewed the questionnaire for content validity. The instrument was pilot tested on a small sample of parents. The results revealed that the questions were clear, appropriate, and acceptable to the respondents. Testing for interrater reliability was not required since all interviews were to be conducted by the same person.

The questions were designed to elicit information on the demographic characteristics of the subjects and on the six research questions previously outlined. Several of the questions yielded

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nominal data. For example, parents were asked to answer either “Yes” or “No” to the question, “Were the good features of the Hickman (or port) discussed with you?” In other instances, questions elicited ordinal data. For example, for the question, “How well did you understand the purpose of having a line put in?”, parents could choose “very well,” “fairly well,” or “not at all well.” A few questions, such as those which asked the parent’s or child’s age, yielded ratio data. Finally, some open questions were included to allow the respondents to describe the experience of caring for their child in their own words and to express additional concerns or offer suggestions for improvement in the care provided by the health professionals. The questionnaire was used to collect data during telephone interviews which were conducted by an experienced interviewer. In addition, some demographic data, such as the child’s diagnosis and current health status, were obtained from child health records. The summarizing program of SPSS for Windows (1996) was used to describe the data according to frequency distributions and cross tabulations. These were needed to address questions 1, 2, 3, 4, and 6. Chi square tests were performed to analyze the data pertaining to question 5. Responses to the open-ended questions were thematically analyzed to identify common emotional responses to the overall experience, as well as common concerns and suggestions for improvements in the professional services.

Results

Response rate and characteristics of the sample

Forty-four parents responded to the questionnaire yielding an overall return rate of 88%. The majority (86%) of the respondents were the mothers of the children. At the time of the child’s diagnosis, the mothers’ mean age was 34 years and their ages ranged from 19 to 49 years. Eighty-four per cent (n=37) were either married or living common-law, and 79% (n=35) had at least a high school education. In comparison, the mean age of the fathers was 36 years and their ages ranged from 21 to 50 years. Seventy-five per cent (n=33) had completed high school. Slightly more than one-half of the families (n=24) lived in the St. John’s or eastern regions of the province at the time of diagnosis. Mothers were the caregivers who spent the most time caring for their ill children. However, fathers, grandmothers, grandfathers, sisters, brothers, aunts, uncles, and friends also provided some care. At the time of diagnosis, the children’s ages ranged from one to 19 years, with an average age of eight years. The majority (61%, n=27) were males. The children suffered from many different types of cancer, the most common being brain tumours (18%), non-Hodgkin’s lymphoma (16%), and acute lymphoblastic leukemia (14%). Thirty-four per cent (n=15) of the children had Hickman catheters, 52% (n=23) had implanted ports, and 14% (n=6) had both types of catheters inserted. The latter group had the catheter insertions performed on separate occasions. Seventy-three per cent (n=32) had a catheter in place for an average of 15 months. The remainder (n=12) still had the lines in place at the time of the study, even though all but one had completed their treatments. Parents reported multiple reasons for the insertion of the catheter including blood withdrawal (30%, n=13), and/or the administration of chemotherapy (98%, n=43), antibiotics (30%, n=13), blood products (21%, n=9), and/or intravenous fluids (14%, n=6).

Results pertaining to questions #1 and #2

Ninety-one per cent (n=40) of the parents stated that a health professional had discussed central lines with them prior to insertion. They reported that the information given by the oncology nurse, the surgeon, and/or the oncologist, was sufficient to ensure they could give informed consent for the procedure. Ninety-eight per cent (n=43) felt they had been fully informed about the purpose of having a line inserted; 59% (n=26) said they understood the purpose very well and 41% (n=18) stated they had a fair understanding of the purpose. Over one-half of the parents (55%, n=24) indicated that they had received

verbal information from other families whose children had CVADs. Of these, 75% (n=21) found the conversations very helpful, 13% (n=3) found them somewhat helpful, and 13% (n=3) reported them not helpful.

The majority of parents also reported that they had received pre-surgical teaching about the features of central lines. This applied to 91% (n=37) of parents of children with Hickman catheters and 75% (n=33) of those whose children had ports. Eighty-four per cent (n=37) stated that the complications associated with central lines had been reviewed. Most parents (89%, n=39) had an opportunity at this time to ask questions, and the majority of these (92%, n=36) felt their questions had been fully answered.

Results pertaining to question #3

Sixty-four per cent (n=28) of the parents indicated that they had participated in the decision regarding the type of central line that was inserted. The decision was made jointly with their spouse (30%, n=13), family and hospital staff (16%, n=7), hospital staff (7%, n=3), spouse and child (7%, n=3), or another family member (2%, n=1). Only one parent made the decision alone. The choice of device for the remaining children (36%, n=16) was made by the hospital staff without parental input. In some cases, older children (45%, n=20) participated in the decision-making. Among these, 48% (n=12) contributed a lot and 32% (n=8) did so a little.

Results pertaining to questions #4 & #5

To address these questions, the parents were first asked to rate, on a three-point scale, their level of satisfaction with the type of CVAD used by their children. The vast majority of parents were highly satisfied, regardless of type of CVAD.

Slightly more parents of children with implanted ports (93%, n=26) reported being “very satisfied” compared with parents of children with Hickman catheters (90%, n=18), but this difference was not significant. Other findings, however, suggest greater satisfaction among the parents of children with ports. For example, when parents were asked what type of CVAD they would choose should their child need it in the future, 67% (n=29) named the implanted port. Only 19% (n=8) would choose the Hickman catheter and the remainder (14%, n=6) stated they did not know.

Further indirect evidence of greater satisfaction with the port device is suggested by results which show that almost all of the parents (97%, n=28) who had experience with implanted ports would choose them again. On the other hand, among the parents who had experience with Hickman catheters, only 40% (n=8) would select this type of device in the future. Of the remainder, 30% (n=6) would request a port and 30% (n=6) were uncertain. This preference for implanted ports was strong and statistically significant [$X^2 = 35.95$, $df = 42$, $p < .000$].

Results pertaining to question #6

Children with Hickman catheters require ongoing catheter care at home. The vast majority (95%, n=19) of the parents of these children reported that they were taught to care for their child’s catheter. All of these parents felt that the amount of teaching was sufficient and that their questions had been answered. While many parents (58%, n=11) were initially nervous in caring for the Hickman catheter, all felt very capable once they had been taught the necessary procedures. By the time they were caring for their children independently, 63% (n=12) felt very comfortable and 37% (n=7) moderately so. The parents were taught catheter care by the oncology nurse (89%, n=17), a hospital nurse (21%, n=4), and/or a community health nurse (16%, n=3).

All but one parent reported that they had a health professional to contact if they had problems and that s/he was helpful. In most cases, this person was the oncology nurse (73%, n=35). Other reported contacts were with the oncologist/surgeon (13%, n=6), hospital nurses (8%, n=4), and community health nurses (6%, n=3).

Other findings

In an attempt to explore factors that might influence satisfaction with the choice of CVADs, the parents were asked to describe their perception of the advantages, disadvantages, complications, and other negative consequences of their child's device. Their responses revealed that both kinds of central lines had major effects on the children and their families. However, the type and/or severity of the consequences differed according to which type of catheter was used. For example, Hickman catheters interfered with bathing, whereas implanted ports did not. These catheters also interfered more with play and sports activities than did ports.

The two devices were also appraised differently in terms of their effect on the child's comfort level. For instance, almost half (45%, n=9) of the children with Hickman catheters became upset when their protective dressings were changed. This did not apply to children with ports since this implanted device does not require dressings. On the other hand, 45% (n=13) of children with ports became upset when needles were used to access their central lines, a procedure that is not required among children using a Hickman catheter.

Other interesting findings revealed that almost half (43%, n=9) of the parents of children with Hickman catheters reported complications, such as accidental removals or infection. Only 24% (n=7) of those caring for children with ports had complications, primarily catheter blockages. The potential for problems such as these created some anxiety for the parents.

Discussion

The high degree of satisfaction for aspects of this program of support and education for the parents lends weight to the notion that such programs are beneficial and should be continued. If so, every effort should be made to acquire or maintain the funding and other resources needed to provide this service in all institutions caring for children with CVADs.

It is noteworthy that over one-third of the parents in this study had not participated in the decision regarding which type of catheter would be used. This may be related to the fact that in some instances

there was no choice. Moreover, there were times when the catheters had to be inserted while the child was undergoing surgery and there was no opportunity to ask the parent's preference. Except in rare circumstances such as these, every effort should be made to involve parents in the decision-making.

As noted earlier, there was overall satisfaction with the type of central line used. Nonetheless, the Hickman catheter was considered more problematic and the parents of children using this type of device tended to experience more anxiety. Clearly, the relative superiority of the implanted ports cannot be established on the basis of these findings nor was this study designed to do so. The results do alert us to the need for further research to compare the effectiveness of the two devices in terms of their benefits, negative consequences, and cost-effectiveness.

Parents were generally satisfied with the teaching and support they received regarding the care of the catheter at home. It was interesting to note that few local resource people (e.g. community health nurses) were used for ongoing teaching and support, even though these health professionals are readily accessible in every community of the province. Parents may not be aware of this resource or may prefer to deal with the health professionals who cared for them and their child in the hospital, regardless of how far away they live.

The findings of this study apply only to the education and support program offered at a specific hospital. As such, they have limited generalizability. The results must also be interpreted cautiously because the data were based on the parents' recall of events they had experienced, in some cases, several years previously.

Despite these limitations, the findings clearly suggest that well developed education and support programs may be very helpful and could be considered an essential part of the services provided. Such programs, however, should be developed with an evaluation component designed to assess their effectiveness on an ongoing basis. This would ensure that parents can give immediate feedback on their experiences and identify any unmet needs which could then be promptly addressed.

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