

Developing a Family-Level Intervention for Families of Children With Cancer

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Purpose/Objectives: To determine the feasibility and effectiveness of a family-level intervention for parents of children newly diagnosed with cancer.

Design: A one-group, pretest and post-test, quasi-experimental design.

Setting: A university hospital in Iceland.

Sample: 10 families (19 parents) of children and adolescents newly diagnosed with cancer.

Methods: Parents were asked to answer questionnaires at baseline and then twice after the intervention, at 6 and 12 months.

Main Research Variables: Acceptability and short-term effects on parents' well-being, coping behavior, hardness, and adaptation of an educational and informational home page, support offered on the Internet to parents, and one or two 60- to 90-minute support interviews.

Findings: Most of the families indicated that the intervention was important, helpful, and supportive, but the level of usefulness of the intervention varied. Information from the hypotheses testing, that parents' level of well-being increased significantly one month after the intervention and that fathers found it helpful to maintain social support and psychological stability after the intervention, are optimistic indicators and support a possible short-term effect of the intervention.

Conclusions: Offering a family-level educational and support intervention was feasible and may be effective for such families.

Implications for Nursing: Researchers and clinicians may want to enhance the intervention and test it on bigger samples and with a control group.

Key Points . . .

- ▶ A family-level educational and support intervention for families of children newly diagnosed with cancer can have an impact on parents' well-being.
- ▶ Healthcare professionals need to be aware of the usefulness of Web-based information for parents and the helpfulness of support interview(s) for families.
- ▶ Fathers use different coping patterns over time.

empowerment of healthy siblings of children with cancer (Murray, 2001), school reentry for children with cancer (McCarthy, Williams, & Plumer, 1998), crisis-intervention strategies (Hendricks-Ferguson, 2000), and reduction of child distress during invasive procedures in childhood leukemia (Kazak, Penati, Brophy, & Himelstein, 1998). Those phenomena are important to research and clinical practice, but the research literature on families of children with cancer needs to be broadened by including interventions for families as a whole when they are dealing with and adapting to childhood cancer. According to Kazak (2004), evidence exists in many healthcare centers that because of limited resources and cost containment since the 1990s, the amount and variety of psychosocial support provided to families have declined. At the same time, families in modern societies are growing more diverse and family life is becoming complex, emphasizing even further the need for informational and psychosocial support for family members when adapting to cancer in children.

Family relations and the impact that family members have on one another are of primary importance when interventions are offered to families dealing with tragic life experience such as cancer in a child family member. In a study on psychosocial needs of families of children with cancer, Ljungman et al. (2003) found that parents and adolescents with cancer rated paper-based, telephone, computer compact

Having a child diagnosed with cancer is one of the most difficult and painful life experiences for a family. From very early on, families of children diagnosed with cancer often have to be involved in complex treatment procedures and deal with their own feelings and insecurity at the same time. Involving families in health care requires collaboration between healthcare professionals and family members. Models of healthcare delivery, such as family-centered care, have become standard in providing high-quality health care for children undergoing cancer treatment. Such models emphasize providing information and fostering and supporting the active inclusion of parents in their children's treatment and management (Holm, Patterson, & Gurney, 2003; Landspítali University Hospital, 2005). To receive this standard of care, families of children with cancer need family-centered interventions that are effective and appropriate to the healthcare services offered (Polit & Beck, 2004; Whittemore & Grey, 2002).

Research focusing on surviving childhood cancer has emphasized interventions concentrating on the psychosocial

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disc (CD), and interactive Web-based intervention packages to be acceptable and accessible ways to meet their needs. Furthermore, in an overview article on psychoeducational interventions for children with chronic disease and their families, Barlow and Ellard (2004) found evidence of effectiveness of interventions incorporating cognitive-behavioral techniques on variables such as family functioning and psychosocial well-being.

Over time, psychosocial interventions may help parents to cope with ongoing stresses and enhance their adaptation to their children's cancer. However, only a few such interventions for families dealing with childhood cancer have been developed for the family as a unit. Those who have developed such interventions have reported conflicting results. Hoekstra-Weebers, Heuvel, Jaspers, Kamps, and Klip (1998) studied the impact of reducing psychological distress in parents of children with cancer in a randomized, longitudinal intervention study. Thirty-nine parents were assigned randomly to an intervention group and 42 parents to a control group. The intervention consisted of eight 90-minute sessions during the first six months after diagnosis (a three-week interval between sessions). The intervention was psychoeducational, using cognitive-behavioral techniques. The results indicated no short- or long-term effects of the intervention. The authors concluded that a more flexible intervention, addressing the more immediate needs and worries of parents, might be more appropriate.

Similarly, Kazak et al. (1998) developed an intervention for adolescent survivors of cancer, their parents, and their siblings. The intervention consisted of four sessions (one day each session) of family group intervention that combined cognitive-behavioral and family therapy approaches. The goals were to reduce symptoms of distress and improve family functioning and development. The intervention was tested among 150 adolescent survivors who had completed treatment 1–10 years previously, their parents, and their siblings, who were randomized to a treatment or wait-list control condition (Kazak et al., 2004). Families randomized to the treatment group received the intervention approximately four to six months after baseline data collection, and a postintervention evaluation took place about three to five months after the intervention. The results supported the brief intervention to reduce post-traumatic stress symptoms in the families and provided additional support for the importance of intervention for multiple members of families.

Even though an intervention focusing on reducing stress symptoms over a longer period of time (10 years) for families of children diagnosed with cancer has been found to be helpful to the families, family-centered interventions that focus on parents' well-being, coping strategies, resiliency, and strength within the family unit and adaptation have not yet been developed to the authors' knowledge. Families of children newly diagnosed with childhood cancer face many challenges, such as emotional disturbances and poor well-being (Sahler et al., 1997; Svavarsdottir, 2005a). Therefore, at the beginning of treatment specifically, focusing on the expression of emotions and coping strategies might contribute to positive family adaptation.

Coping with childhood cancer has to be considered a process in which all family members are engaged. In the literature, coping has been referred to as efforts to manage demands regardless of the success of the efforts (Lazarus & Folkman,

1984). Coping strategies are not adaptive or maladaptive in and of themselves. Their adaptability has to be determined by their outcomes, by the best fit of the particular coping strategy to the demands of the situational factors, and by personal factors. Parents of children newly diagnosed with cancer need to cope with their situations, care for their own well-being, and adapt to their children's health status. Families with high resiliency factors, such as hardiness, might have an easier time adjusting if they view changes as growth producing, develop a sense of control over their outcomes in life, and use an active rather than passive orientation in adapting to the cancer situation (McCubbin & McCubbin, 1996), which emphasizes the importance for healthcare professionals to empower resiliency and support strengths in families.

The Intervention

Theoretical Framework

The family-level support component of the intervention was based on the Calgary Family Intervention Model (CFIM) (Wright & Leahey, 2000). The CFIM has its foundation in postmodernism, system theory, cybernetics, communication, change theory, and the theoretical basis of biology of cognition, which emphasizes that humans bring forth different views to their understanding of events and experiences in their lives (Maturana & Varela, 1992). In the CFIM, interventions can be targeted to promote, improve, or sustain functioning in any or all of the three domains of family functioning (cognitive, affective, and behavioral). Change in one domain is viewed as affecting another domain. Wright and Leahey believed that the most profound and sustaining change is the one that occurs in the family's beliefs (cognition). The CFIM emphasizes that nurses can only offer interventions to families. Whether families open space for interventions depends on their character and history of interactions among family members. Openness to particular interventions also is deeply influenced by relationships between nurses and families and nurses' ability to encourage families to think about their health problems. The intervention process provides an appropriate context in which families can make necessary changes. Nurses should tailor their interventions to each family and to the chosen domain of family functioning. Therefore, interventions usually vary among families because, in the model, each family is viewed as unique.

The purpose of this study was to test whether a family-level educational and support intervention for parents of children and adolescents newly diagnosed with cancer would improve mothers' and fathers' well-being, coping, family hardiness, and adaptation over a period of six months (short-term effects) and at a one-year follow-up. The researchers hypothesized that mothers' and fathers' (a) well-being would increase significantly after the intervention; (b) use of coping patterns regarding maintenance of family cohesion, cooperation, social support, psychological stability, and understanding of the medical situation would increase significantly after the intervention; (c) use of coping patterns would be significantly different before the intervention, after the intervention, and at the one-year follow-up; and (d) family hardiness and adaptation would differ significantly before (baseline) compared to after the intervention and at the follow-up intervention measurement.

Methods

Design

A one-group, pretest and post-test, quasi-experimental design was used. Mothers and fathers of children or adolescents who had been diagnosed with cancer within two months prior to the intervention answered questionnaires before the intervention (at baseline) regarding their own mental health, hardiness, coping behaviors, and adaptation. The intervention (the interview[s] and the use of the parents' Web-based education and support) was offered over a period of approximately four to five months for each family; the parents answered the questionnaires again at six months (time 1) (about one month after the intervention) and at one year (time 2). Parents also answered questions regarding the usefulness of the home page, the support on the Internet, and the support interviews after the intervention (time 1).

Procedure

Data were collected over a period of 26 months. Of 14 families who had a child or an adolescent diagnosed with cancer in Iceland during the time period, 12 families met the study criteria and were offered a chance to participate in the intervention study. Two of the 12 families declined participation, resulting in a sample of 10 families (83% participation). Data were collected from 19 parents (10 families) at baseline; 18 parents (nine families) participated at six months and 9 parents (five families) participated at one year. The inclusion criteria were as follows: The parents had to speak Icelandic fluently, the children had to be younger than 18 years and newly diagnosed with cancer, and families had to receive their cancer-related healthcare services from the Children's Hospital at Landspítali University Hospital (LUH) in Reykjavik, Iceland. The children could not have any other physical or mental illnesses. The research was approved by the institutional review board of LUH, and it was reported to the Data Protection Committee.

Families were introduced to the study at the Children's Hospital at LUH. Those who agreed to participate and gave their written consent received a package of questionnaires and a password to enable them access to a specially developed Web site that was part of the intervention. Mothers and fathers received different passwords so they could access the Web site independently at their own convenience. The families were offered a support interview after having had access to the Web site for about a month. In all cases, both parents participated in the support interview, which lasted 60–90 minutes. All of the families were offered a second support interview about two to four months after the first support interview (depending on the needs of the families). Each of the second support interviews also lasted 60–90 minutes. All families received one support interview, and five of nine families (56%) received two support interviews (two families had lost their children by time 1).

Eight of the 10 families had their own computers and Internet connections at home. The two families that did not have a computer or Internet access were offered a computer, and a technician went to the homes of those families to connect the computers to the Internet. The support interviews took place at the Institute of Nursing Research at the University of Iceland located next to the Children's Hospital at LUH.

A pilot, family-level educational and support intervention was developed to provide a context for informing parents about cancer and improving psychological well-being and adaptation for parents of children newly diagnosed with cancer. For the educational component of the intervention, an informational Web site was developed, where parents could look up information about various types of cancer and its effects on families. The educational component of the Web site was developed on the basis of existing literature and the professional expertise of physicians and clinical nurse specialists (specialists in oncology nursing) employed at LUH.

Intervention Development

The family-level educational and support intervention was developed for parents of children and adolescents with cancer. The intervention consisted of three phases. First, a 137-page educational and informational Web site was developed, focusing for example on individuals', siblings', and parents' experiences dealing with childhood cancer as well as on practical issues regarding cancer, such as treatments, management, and future concerns about medical side effects. Parents could look up information, at their own convenience, about various types of cancer and its effects on children and family members. The Web site was open during the time period of the study, and new information was added to the Web site every week for the first 10 weeks of the study. Second, support was offered to the parents via the Internet. The parents could interact with each other about their concerns without participation from the research team, or the parents could interact with the research team directly on an individual basis (without the other parents being able to follow the discussion) or with the research team such that other parents could follow and participate in the discussion. Third, each family was offered one or two 60- to 90-minute support interview(s), depending on the parents' need for support. The support interview was introduced to the parents as an opportunity for them to engage in a therapeutic relationship. A nurse researcher with a doctoral degree in family nursing and a clinical nurse specialist in pediatric cancer nursing conducted the interviews.

The support interview(s) had four main foci: (a) to invite the parents to engage in a therapeutic relationship; (b) to inform parents about evidence-based research findings related to coping, well-being, resiliency, and adaptation for families dealing with childhood cancer; (c) to give parents the opportunity to discuss issues of concern to them and to answer specific questions on the parents' minds related to the health situation of their children; and (d) to facilitate a context where families could make small or significant changes by having the interventionist encourage the family members to think differently, encourage different means of affective expressions, and ask families to perform new tasks. For the interviews to be supportive for the families, the interventionist had to ask interventional questions that stimulated therapeutic conversation, empowered family members, and expressed confidence in their problem-solving abilities.

The content of the first support interview started with an introduction of the interview, and results were presented from earlier longitudinal research on family adaptation for Icelandic families of children and adolescents with cancer (Svavarsdóttir, 2005a, 2005b). The findings, based on gender differences in coping with childhood cancer and emotional support, were introduced to the parents. Concepts such as adaptation and

coping were presented and research findings introduced that focused on coping strategies, well-being, and adaptation for families of children and adolescents newly diagnosed with cancer. The parents then described their families' size and relationships and the length of their marital relationships. All of the parents also described their experiences of having their children diagnosed with cancer, their social support systems such as friends and extended family, their employment status, their relationships with coworkers, and their financial situations. Both parents talked about how each was managing being employed (if that was the case) and caring for a child with cancer at the same time. The parents described how they managed to take care of their other children and be constantly at the hospital at the same time and how the siblings (if applicable) were dealing with the situation. They also discussed their worries, how the cancer diagnosis had affected them emotionally, how they coped with the experience at the time, and what was working for them as a couple and as a family. Communication and relationships with other families in the same situation also were discussed. Responses from friends, extended family members, coworkers, healthcare professionals, teachers, schools, and society in general were mentioned frequently by the parents. Mothers and fathers found that reflecting on each other's experiences was helpful when describing communications with any of those individuals.

The second support interview had the same focus as the first (except that the first two steps were not repeated). In the second interview, parents were asked how the children, they themselves, and other members of their families had been doing since the first interview (both parents were invited to speak). The parents also were asked whether anything specific was on their minds and how the next weeks and even months looked to them. Mothers and fathers were given time to reflect on their own experiences, discuss worries and concerns, and express how they were coping and what was most helpful to them at that time. The parents also were given a chance to discuss specifically how other family members (such as siblings and their extended families) and friends were handling the situation. In the interview, the parents also were given the opportunity to discuss how (if at all) the experience of having a child diagnosed with cancer had changed them or their beliefs and how they were planning to resume "normal" life again.

The role of the interventionist was to reflect on the parents' experiences by asking relevant circular questions, encouraging, empowering, and pointing out in what way the families were handling their situations well. The interventionist also listened to the parents' stories of their experiences, pointed out differences between the parents, and answered specific questions asked by the parents. In general, the interventionist had to create a context in the interviews where families could make small or significant changes by recognizing their problem-solving abilities and by realizing that interventions are focused on cognitive, affective, or behavioral domains of family functioning. The interventionist had to encourage family members to explore alternative solutions to problems, invite them to think differently, encourage different affective expressions, and ask families to perform new tasks. The interventionist used questions as interventions, empowered and supported the families, and expressed confidence in their problem-solving abilities. The clinical nurse specialist who participated in the support interviews primarily assumed the

role of answering parents' practical questions regarding cancer treatments and management.

Statistical Analyses

Descriptive statistics were calculated for the major study variables (coping strategies, well-being, family hardness, and adaptation), as well as for the demographic variables. Separate statistical models were run for mothers and fathers. Paired *t* tests were used to test the hypotheses regarding mothers' and fathers' well-being, their use of coping strategies, and possible gender differences between the parents on their perception of their families' hardness and adaptation. Because only five families remained at one year, no statistical hypotheses testing on study variables was performed, but descriptive statistics were compiled. To evaluate short-term effects of the intervention, paired *t* tests were used to measure mean differences between baseline data and data gathered after the time 1 intervention. Statistical significance was set at $p < 0.05$.

Instruments

The questionnaires were developed in the English language. To collect data from the Icelandic families, the instruments were translated from English to Icelandic and then back-translated into English by a team of translators and healthcare professionals. All of the Icelandic instruments were pilot tested on three families of children with cancer.

Demographic data were obtained from both parents. Information specific to the children's cancer conditions, such as cancer medications, pain medications, antiemetic drugs, surgery to remove tumors, hospitalization and support groups, was gathered using the **Cancer Factor Index**, a 24-item questionnaire (Svavarsdottir, 1999).

The **General Well-Being Schedule** (GWB) (Dupuy, 1977) was used to measure mothers' and fathers' well-being. The GWB was developed to assess how individuals feel about their inner personal states. The scale consists of 18 items that include positive and negative questions for six dimensions: anxiety, depression, general health, positive well-being, self-control, and vitality. Each item in the questionnaire has the time frame "during the last month." The reliability and validity of the GWB have been supported in numerous studies (McDowell & Newell, 1987). The reliability of the scale for American parents has been reported to be 0.91 for mothers and 0.94 for fathers. For the Icelandic version of the scale, the internal reliability was 0.86 for mothers and 0.91 for fathers.

The **Coping Health Inventory for Parents** (CHIP) (McCubbin, McCubbin, Nevin, & Cauble, 1996) is a 45-item checklist that provides self-report information about each parent's effectiveness in coping with a child's illness. Respondents are asked to indicate how helpful (from 0 = not at all to 3 = very helpful) each coping strategy has been in managing the illness situation. Three scales were constructed using factor analysis: I. maintaining family cohesion, cooperation, and an optimistic definition of the situation; II. maintaining social support and psychological stability; and III. understanding the medical situation by communication with the staff or with other parents. The CHIP has demonstrated good psychometric properties, with internal consistency scores (Cronbach's alpha) of 0.75, 0.76, and 0.71, respectively, for the three scales in a German translation (McCubbin, McCubbin, Nevin, et al., 1996). For the Icelandic version of the questionnaire, internal

consistency scores ranged from 0.67–0.79 for mothers and 0.79–0.83 for fathers.

Family strength and resources were measured by the **Family Hardiness Index (FHI)** (McCubbin, McCubbin, & Thompson, 1996). The 20-item instrument consists of three sections: commitment to, challenge of, and control over family life. Respondents note the degree to which each statement describes the current family situation on a 0–3 scale. Higher scores on the instrument are indicative of positive perceptions of family hardiness. Validity for the FHI has been well described; the internal reliability for the FHI is 0.82 (McCubbin, McCubbin, & Thompson). In a study of families of children with asthma, Cronbach's alpha was 0.86 for U.S. mothers and 0.84 for U.S. fathers. For the Icelandic sample, the alpha reliability was 0.81 for mothers and 0.76 for fathers.

Family adaptation was measured by the 11-item **Family Adaptation Scale (FAS)** (Antonovsky & Sourani, 1988). Each item is scored from 1 (completely satisfied) to 7 (not satisfied), with negative items reverse-scored for inclusion in the summary score. As with the other scales, mothers and fathers responded separately and individual scores were calculated. In the FAS, six items refer to satisfaction with internal family fit (individual to family unit), two items refer to family-community fit, and three items cover both levels of fit. Internal reliability has been reported to be 0.89 for the whole scale. In a U.S. sample, the alpha reliability for mothers was 0.88 and 0.89 for fathers. In the Icelandic sample, Cronbach's alphas were 0.79 and 0.89 for mothers and fathers, respectively.

Results

Participants

Parental characteristics: The mean age of the mothers was 37.5 years (SD = 6.10), and their average education was 15.57 years (SD = 2.82). Most of the mothers (90%, n = 9) were working part- or full-time outside the home at the time of the study. All of the mothers were Icelandic (100%), and 90% (n = 9) were married or cohabiting. The fathers' mean age was 39.44 years (SD = 8.02), and their mean education was 14.57 years (SD = 4.61). Most of the fathers worked full-time or worked full-time and had a second job (70%; n = 7). All of the fathers were Icelandic, and 80% (n = 8) of the fathers were married or cohabiting with their partners. The parents had two children on average in their present marriages or relationships, and the mean length of their relationships or marriages was 12.63 years.

Child characteristics: The average age of the children at the time of cancer diagnosis was 10.88 years (SD = 6.98). Most of the children or adolescents were female (70%; n = 7). All of the children were receiving cancer treatment at the time of the study. Eight children (80%) needed pain medication, eight were on antiemetic drugs, one was awaiting surgery to remove a tumor, and one needed radiotherapy. The type of cancer diagnosis varied: One child had lymphoma, 50% (n = 5) had lymphocytic leukemia, two had brain tumors, and two had sarcoma (osteosarcoma and rhabdomyosarcoma).

Short-Term Effects of the Intervention

For the mothers, a significant difference was found in their levels of well-being before (\bar{X} = 60.56) and after (\bar{X} = 76.33; p = 0.005) the intervention. Also, a significant difference was found in fathers' well-being before (\bar{X} = 64.44) and after (\bar{X} = 75.56; p = 0.009) the intervention (see Table 1).

Table 1. Mothers' and Fathers' Coping Behavior, Well-Being, Family Hardiness, and Adaptation Before and After the Intervention

Variable	Before	After	t	p
	\bar{X} (SD)	\bar{X} (SD)		
Mothers (n = 9)				
Coping pattern I	45.89 (8.81)	47.33 (5.50)	-0.54	0.603
Coping pattern II	31.67 (9.76)	32.44 (6.48)	-0.36	0.727
Coping pattern III	17.33 (3.67)	16.78 (4.74)	0.26	0.805
Coping (total score)	94.89 (15.14)	96.00 (9.73)	-0.24	0.816
Family hardiness	46.22 (5.45)	44.56 (3.28)	0.92	0.384
Well-being	60.56 (14.58)	76.33 (14.51)	-3.88	0.005
Adaptation	57.11 (8.67)	56.33 (8.94)	0.37	0.723
Fathers (n = 9)				
Coping pattern I	42.75 (7.70)	45.38 (5.55)	-1.12	0.301
Coping pattern II	26.88 (9.75)	31.50 (6.44)	-2.16	0.067
Coping pattern III	17.00 (3.89)	15.75 (3.92)	1.16	0.286
Coping (total score)	86.63 (16.54)	92.63 (11.49)	-1.47	0.184
Family hardiness	44.00 (6.86)	43.89 (4.78)	0.07	0.945
Well-being	64.44 (16.31)	75.56 (16.65)	-3.39	0.009
Adaptation	57.00 (10.01)	53.56 (9.53)	1.52	0.166

Fathers' use of coping pattern II before and after the intervention approached significance (p = 0.067), indicating that fathers found it more helpful to maintain social support and psychological stability after the intervention compared to before the intervention. No significant difference was found in the fathers' use of coping patterns I and III or on the total coping score before and after the intervention. No significant differences were found in the mothers' use of coping patterns I, II, and III or on the total coping score before and after the intervention.

Gender Differences

No significant difference was found between mothers' and fathers' use of coping patterns I, II, and III before or after the intervention at time 1 (six months). However, when the means for the parents' coping strategies were compared at baseline, six months, and one year, the fathers decreased their use of coping pattern II at one year, compared to their use of that particular coping pattern at six months, indicating that fathers found it helpful to use different coping patterns over time (see Tables 2 and 3).

No significant difference was found between mothers' and fathers' family hardiness or between mothers' and fathers' adaptation before and after the intervention. When the parents' mean scores at time 2 were compared to the baseline data and to the data at follow-up, mothers' perception of their family hardiness and adaptation decreased (about four units). The fathers' perception of their family hardiness, from baseline to follow-up, did not change, but the fathers' perceptions of their family adaptation did decrease a little (about two units) from baseline to the follow-up intervention measurement.

Parents' Evaluation of the Educational and Support Intervention

Use of the educational and informational part of the Web site: The parents were asked to evaluate how accessible, understandable, helpful, and useful the educational and informational

Table 2. Comparison of Parents' Well-Being, Coping Behaviors, Family Hardiness, and Adaptation Before and After the Intervention (Short-Term Effect)

Variable	Mothers (n = 9)	Fathers (n = 9)	t	p
	\bar{X} (SD)	\bar{X} (SD)		
Before intervention (Baseline)				
Coping pattern I	47.00 (8.72)	42.75 (7.70)	1.48	0.181
Coping pattern II	30.50 (9.74)	26.88 (9.75)	1.49	0.180
Coping pattern III	17.75 (3.69)	17.00 (3.89)	0.61	0.559
Coping (total score)	95.25 (16.14)	86.63 (16.54)	1.93	0.094
Family hardiness	46.22 (5.45)	44.00 (6.86)	0.98	0.352
Well-being	60.56 (14.58)	64.44 (16.31)	-0.67	0.521
Adaptation	57.11 (8.67)	57.00 (10.01)	0.03	0.979
After intervention (Time 1)				
Coping pattern I	47.33 (5.50)	44.89 (5.40)	1.14	0.289
Coping pattern II	32.44 (6.48)	31.44 (6.02)	0.48	0.645
Coping pattern III	16.78 (4.74)	14.78 (4.68)	0.99	0.350
Coping (total score)	96.00 (9.73)	91.11 (11.67)	1.15	0.283
Family hardiness	44.56 (3.28)	43.89 (4.78)	0.36	0.727
Well-being	76.33 (14.51)	75.56 (16.65)	0.14	0.895
Adaptation	56.33 (8.94)	53.56 (9.53)	0.74	0.481

part of the Web site was to them after the intervention (time 1). Most of the families accessed and made use of the educational and informational part of the Web site. The site was visited 332 times over the period of the study, about 12 times per month. Of the parents, seven mothers (78%) and five fathers (56%) answered questions regarding their use of the information and support on the Internet. Five mothers (71%) and four fathers (80%) reported the educational part of the Web site to be rather accessible or accessible; six mothers (86%) and four fathers (80%) reported that the information presented was rather understandable or understandable; five mothers (71%) and three fathers (60%) said the information was rather helpful or helpful; and five mothers (71%) and three fathers (60%) said the information was rather useful or useful. Seven mothers (100%) and four fathers (80%) reported using the informational and educational part of the Web site one to five times per month; one father (20%) reported using it 6–10 times per month.

Table 3. Parents' Well-Being, Coping Behaviors, Family Hardiness, and Adaptation After an Educational and Support Intervention at One Year

Variable	Mothers (n = 9)	Fathers (n = 9)
	\bar{X} (SD)	\bar{X} (SD)
Coping pattern I	49.60 (5.13)	45.50 (5.74)
Coping pattern II	32.40 (7.60)	24.00 (9.90)
Coping pattern III	15.40 (4.34)	13.70 (5.50)
Coping (total score)	96.00 (4.74)	84.50 (5.92)
Family hardiness	42.00 (4.00)	42.50 (8.66)
Well-being	76.20 (7.46)	78.00 (8.08)
Adaptation	48.20 (8.26)	55.00 (9.09)

Evaluation of interactive Web-based support and support interview(s): Parents were asked to evaluate how helpful they found the interactive Web-based support to be after the intervention. The interactive Web-based support (defined as communication between the parents with or without participation of the research team) was found to be helpful by one mother (14%) and one father (20%); one mother (14%) also reported that the support provided via the Internet was useful, but no fathers reported it to be useful. Four mothers (57%) and three fathers (60%) reported using the support on the Internet one to five times per month.

Mothers and fathers also were asked to evaluate the support interview(s). Eight families (14 parents) reflected on it in writing in response to an open-ended question regarding their experiences of receiving support interview(s). All of the parents were thankful for being offered such support interview(s) and thought the interview(s) was/were helpful to them. One mother described her experience of the support interview(s) as

Very helpful and supportive. We were so insecure; the interviews gave me and my family hope about the future and increased our strengths to keep up with our daily life. We are more hopeful now that we will handle our experiences. It was good to have such a caring and understanding atmosphere and to receive the interest from healthcare professionals.

A father described his experience as “supportive and helpful. It opened my eyes to what we were going through. I was under such pressure at the time; I needed this.”

Discussion

When evidence-based healthcare service is delivered to children and adolescents with cancer, family members must be incorporated into healthcare delivery. By transferring effective family nursing intervention into clinical practice, healthcare professionals meet the needs of families to handle tragic life experiences in the most constructive way.

The data presented in this pilot study on the effectiveness and feasibility of a family-level educational and supportive intervention are promising. However, the limitations of the study have to be taken into account. The data are preliminary, the sample was small, and no comparison group was used. Despite the limitations, all Icelandic families of children or adolescents newly diagnosed with cancer over a 26-month time period were offered participation, and a majority of the families who participated evaluated the intervention positively. Mothers and fathers indicated that the intervention was important, helpful, and supportive. The level of usefulness of the intervention varied, however. The educational and informational part of the Web-based intervention was evaluated by seven families. Of those families, most parents thought that the Web-based educational and information part of the intervention was accessible, understandable, helpful, and useful, and a majority of the families used it one to five times per month, supporting its usefulness. However, only four families evaluated the helpfulness of the interactive Web-based support; of those families, only one mother found the support provided via the Internet to be useful. The researchers, therefore, recommend for further testing of the effectiveness of this family-level intervention that the support provided via the Internet should be excluded.

Regardless of little foundation for using support via the Internet, the results on usefulness of the educational and informational part of the Web-based intervention and the positive evaluation of the support interviews are encouraging. The interviews were evaluated by a majority of the parents as being highly supportive to them and their families. Also, information from the hypotheses testing that mothers' and fathers' levels of well-being increased significantly one month after the intervention (short-term effects) is promising, as well as the finding that fathers found it more helpful to maintain social support and psychological stability after the intervention compared to before the intervention. The fact that the families liked the support interviews and found that type of intervention helpful is critical and reassuring. The findings regarding increased well-being after the intervention among both parents also are positive for further testing of the family-level intervention.

To the authors' knowledge, no study has yet tested the short-term effects of a family-level intervention focusing on well-being, coping strategies, resiliency, and adaptation. Even though the findings from this pilot study allow the researchers to draw some conclusions about promising short-term effects of a family-level intervention, findings from the one-year follow-up give some insight into how the families are handling their situations over time. Fathers in the pilot study found social support and psychological stability to be less effective at one year (compared to at six months) when coping with their children's cancer, indicating some variability in fathers' use of coping patterns over time. Also, both parents perceived their family adaptation to be lower (by two to four units) at one year, indicating the need to develop and test long-term effects of a family-centered intervention for families of children and adolescents with cancer.

The family-level data are particularly interesting and encouraging. Earlier research (Svavarsdottir, 2005a, 2005b) has shown that the well-being of parents of children and adolescents with cancer varies over time, and the findings from the current pilot study demonstrate possible effects of a family-level intervention on parents' well-being. Clinically, the positive responses from mothers and fathers regarding the helpfulness of the support interview(s) for their family units are encouraging and support the need for such family-

centered intervention. According to Wright and Leahey (2000), the primary goal of family intervention is to change or alter a family's view of or beliefs about the illness. Therefore, nurses can help family members to search for alternative behavioral, cognitive, and affective responses to problems. One nursing goal is to help families discover their own solutions to problems. The positive reflection of the majority of parents in this pilot study supports the foremost goal of a family intervention. The data from this study of Icelandic families also suggest that follow-up intervention focusing on ongoing psychological health of parents might be helpful long-term for families who are adapting to childhood cancer.

Conclusion

Family members need to have the opportunity to connect with each other when dealing with their experience of serious pediatric illness. The educational and informational Web-based part of the family-level intervention gave parents the opportunity to visit the Web site, get information about their children's diseases, read about them, and talk through their concerns and worries. The support interview(s) then gave the parents a further chance to reflect on their experiences as individuals and from the viewpoint of the wellness of their families. Reflecting on their own experiences and the experiences of their family units and talking openly to spouses about how they are handling their situation can decrease isolation, increase connectedness, and empower families. The authors are optimistic about the short-term effects and the future of this family-level intervention. Excluding the Web-based support from the family intervention and focusing on Web-based education and information for parents and offering parents support interviews (where the frequency would be based on the needs and willingness of each family to participate) will enhance further development of the family intervention. In future research, such an intervention for families of children and adolescents newly diagnosed with cancer needs to be tested with a bigger, randomized sample and a control group.

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