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Title: The Feasibility of using Computer Technology for Mutual Support. A Computer-Mediated Support Group Intervention for Parents whose Children have been Diagnosed with Cancer

Running header: Computer-Mediated Support Group Intervention for Parents

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Association, The Icelandic Cancer Organization, The Icelandic Research Council, The Landspítali-University Hospital.

Precis: Seventeen parents, whose children had been diagnosed with cancer, participated in a computer-mediated support group by using their e-mail.

ABSTRACT

Purpose: The purpose of this study was to evaluate the feasibility of a computer-mediated support group (CMSG) intervention for parents whose children had been diagnosed with cancer.

Design and Methods: An evaluative research design was used with a one group before-and-after design. A CMSG, an unstructured listserve group where participants used their e-mail for communication, was conducted over a four-month period. Participation in the CMSG was offered to parents whose children had completed cancer treatment and were within five years of treatment completion. The study was conducted in Iceland. Outcome measures were done: prior to the intervention (Time 1), after two months of intervention time (Time 2) and post intervention (Time 3). Measures included: demographic and background variables; health related vulnerability factors of parents: anxiety, depression, somatization, and stress; perceived mutual support; and use of the CMSG. Data were collected from November 2002 to July 2003. Twenty-one of 58 eligible parents participated in the study, with 71% retention rate for both post-tests.

Findings: Mothers' depression decreased significantly from Time 2 to Time 3 ($p < .03$). Fathers' anxiety decreased significantly from Time 1 to Time 3 ($p < .01$). Fathers' stress decreased significantly from Time 2 to Time 3 ($p < .02$). To some extent, mothers and fathers perceived mutual support from participating in the CMSG. Both mothers and fathers used the CMSG by reading messages. Messages were primarily written by mothers.

Conclusions: Study findings support further development of CMSGs for parents whose children have been diagnosed with cancer.

Key words: parents, childhood cancer, computer-mediated support group, intervention

INTRODUCTION

Childhood cancer is a chronic disease which has a substantial effect on the child, the parents and other family members (Alderfer, Cnaan, Annunziato, & Kazak, 2005; Brody & Simmons, 2007; Clarke, 2006; Heath, Lintuuran, Rigguto, Tikotlian, & McCarthy, 2006; Kazak et al., 2004; Kazak, Boeving, Alderfer, Hwang, & Reilly, 2005; Lähteenmäki, Sjöblom, Korhonen, & Salmi, 2004; Lou, 2006; Norberg, Lindblad, & Boman, 2005; Ozono et al., 2007; von Essen, Sjödén, & Mattsson, 2004; Wijnberg-Williams, Kamps, Klip, & Hoekstra-Weebers, 2006). Former studies of parents of children with cancer indicate a strong need for mutual support from other parents with comparable experience (Chesler & Chesney, 1995; Lähteenmäki et al., 2004; Ljungman et al., 2003). Face-to-face mutual support groups providing parents with emotional and psychosocial support, and practical information about the disease, treatment, side-effects, and available resources have shown to be of value (Chesler & Chesney, 1995; Foreman, Willis, & Goodenough, 2005). Mutual support can help parents of chronically ill children and other family members to better cope with the child's illness.

In spite of the fact that many parents benefit from participation in face-to-face mutual support groups, a number of parents do not or cannot participate in these groups. Among reasons for non-participation are distance to meeting site and discomfort with expressing themselves in a group (Chesler & Chesney, 1995). Computer-mediated support groups (CMSG) have shown to be a valuable addition to, or substitute for, traditional face-to-face mutual support groups for parents of children with special needs (Baum, 2004; Huws, Jones, & Ingledeu, 2001), and adult patients and family caregivers of adult

patients (Hill & Weinert, 2004; Hill, Weinert, & Cudney, 2006; Klemm & Wheeler, 2005; Meier, Lyons, Frydman, Forlenza, & Rimer, 2007; Radin, 2006). This may also be true for parents of children with cancer, as indicated by one exploratory study on the use of a computer-mediated support group for parents of children with cancer (Han & Belcher, 2001).

The purpose of this study was to evaluate a computer-mediated support group (CMSG) intervention for parents whose children had been diagnosed with cancer in Iceland. Research questions were raised on: a) whether participation in a CMSG decreased parental anxiety, depression, somatization, and stress; b) the extent to which participants perceived mutual support from participating in a CMSG; and c) how frequently participants used the CMSG.

The conceptual framework of this study is based on Flaskerud & Winslow's (1998) vulnerable population model, where parents of children with cancer are defined as a vulnerable population. Yalom's (1985) model of group therapeutic factors, Riessman's (1965) "helper" therapy principle, Vugia's (1991) definition of what happens in mutual support groups, and Caplan's (1979) approach to social support are used to explain what mutual support indicates. The CMSG is a form of the Nursing Interventions Classification (NIC) Support Group defined by Dochterman & Bulechek (2003).

METHODS

A one-group before-and-after evaluative research design was used for this study. Repeated measures were done at Time 1 before the intervention was initiated; at Time 2 after two months of the intervention initiation and continuance; and at Time 3 at the end of the intervention. The CMSG intervention was carried out for four months. Former

studies on CMSG indicate a trial time of 3-6 months (Gustafson et al., 1999; Hill et al., 2006; Hill & Weinert, 2004). The study was conducted at the Landspítali-University Hospital in Reykjavík, Iceland, the only health care facility in Iceland treating children with cancer.

Iceland is a European country with approximately 300,000 inhabitants. Approximately two thirds of the population lives in the capital area of Reykjavík, whereas the rural areas are mainly scattered around the coastal line. Icelanders speak their own language - Icelandic. Technology is highly valued in Iceland. In 2006 84% of Icelandic households had computers and 83% had Internet access (Statistics Iceland, 2007).

The target population was parents of children who were medically diagnosed with some sort of cancer at the age of 18 years or younger, and had completed their treatment and were in close post treatment follow-up as of October 2002. Fifty eight parents of 32 children met the inclusion criteria and were invited to participate in the study. Prevalence of cancer in children in Iceland is comparable to other Western countries. In 1981-1995 186 newborn to 19-year-old children were diagnosed with cancer in Iceland, and of those 139 were 15-year-old or younger, indicating an incidence of 14.6 per 100.000 children (G. Jónmundsson, personal communication, February 14th, 2000).

The participants' right to protection of privacy was observed by gaining required permissions from the Institutional Review Board of the hospital and the Icelandic Data Protection Authority. Participants gave their written informed consent prior to participation.

The CMSG Intervention

The structure of the intervention of the CMSG was a listserv or a mailing list, where participants used their own e-mail addresses for sending and receiving messages. The group had three facilitators: the investigator who is a pediatric nurse, a clinical nurse from the outpatient unit for pediatric oncology, and a social worker with experience in working with families of children with cancer. Only participating parents and the facilitators had access to the group. Participants received written rules for the group which they were asked to read prior to participation. The rules indicated the purpose of the group, that general courtesy was expected, that group discussions were confidential, and that all messages were monitored by the group facilitators. Group discussion was unstructured and parents were encouraged to discuss anything they liked in relation to their experience of being a parent of a child who had been diagnosed with cancer. Parents could stay anonymous as they were not required to identify themselves with names and they could use pseudo names in their e-mail addresses. The role of the group facilitators was mainly to encourage the discussion of parents. Asking participants how their weekend was, or giving them an example on how some people use prayer to cope, were ways to encourage and facilitate discussions.

Data Collection and Analysis

An invitation letter was sent to participants followed by a telephone call where parents were given the opportunity to get further explanations about the study and participation. Four households with parents who indicated they wanted to participate in the study did not have computers at home. These parents were provided with used computers and modems.

Accompanying the invitation letter was a written informed consent form and the questionnaires for Time 1 measures. Five different paper and pencil questionnaires, mailed to participants, were used for data collection: a) The Basic Questionnaire 1 (BQ1), developed by this investigator, used at Time 1 to obtain information on demographic and background variables such as previous participation in a CMSG; b) the SCL-90 subscales on anxiety, depression and somatization (Derogatis, Lipman, & Covi, 1973), used at all three times of outcome measures; c) the Perceived Stress Scale (PSS) (Cohen, Kamarck, & Mermelstein, 1983; Cohen & Williamson, 1988), used at all three times of outcome measures; d) the Perceived Mutual Support Scale (PMSS), used at Time 2 and Time 3; and, e) The Basic Questionnaire 2 (BQ2), developed by this investigator, used at Time 2 and Time 3 to obtain information on participants' use of the CMSG.

The SCL-90 is a five-point Likert-type scale where each subscale gives a total mean score of 0-4. A higher mean score indicates more anxiety, depression, or somatization. The anxiety subscale has 10 items, the depression subscale 13 items, and the somatization subscale 12 items. For the total sample in this study the Cronbach's alpha reliability coefficient for the anxiety subscale, the depression subscale, and the somatization subscale was $>.86$ ($N=21$), $>.90$ ($N=18$), and $>.83$ ($N=20$), respectively. The SCL-90 has been used in other studies on parents whose children have been diagnosed with cancer (Magni, Carli, De Leo, Tshilolo, & Zanesco, 1986; Wijnberg-Williams et al., 2006). The SCL-90 had been translated into Icelandic prior to this study.

The PSS is a 14-item five-point Likert-type questionnaire to measure the degree of stress in people's lives. A total stress score, which can range from 0-56, is calculated for each participant, with a higher score indicating more stress. The Cronbach's alpha

reliability coefficient for the PSS was $>.91$ ($N=19$) for the total sample in this study. The PSS has been used for studying parents (Phua, Reid, Walstab, & Reddihough, 2005), and had been translated into Icelandic prior to this study.

The health related parental vulnerability factors were chosen as outcome measures for the CMSG, based on the results of former studies on parents whose children had been diagnosed with cancer. An extensive integrated literature review analysis done prior to the study, indicated anxiety, depression, somatization and stress to be the most frequently identified vulnerability factors of these parents.

The PMSS was constructed by this investigator based on Weinberg, Schmale, Uken, & Wessel's (1995) study scales, which use Yalom's (1985) group therapeutic factors besides asking about helpfulness. The scale includes 32 statements on: a) helpfulness, b) altruism, c) instillation of hope, d) universality, e) catharsis, and f) group cohesion. Participants are asked to what extent they agree or disagree with statements underpinning the therapeutic factors in the PMSS. Due to the small number of parents answering the PMSS calculation of its reliability coefficient was not possible.

Data analysis was done using the SPSS software. Due to the small sample size and skewed distribution of data, non-parametric statistics were used to interpret research findings. To detect changes over time for anxiety, depression, somatization, and stress, for parents, the Friedman two-way Analysis of Variance by ranks followed by Wilcoxon match-pairs signed-ranks test was used. To detect changes over time in perceived mutual support and use of group, frequency distributions were compared between times with "eye-ball comparison". Based on the results of other studies on parents whose children had been diagnosed with cancer and how they are presented (Kazak et al., 2004, 2005;

Lähtenmäki et al., 2004; Lou, 2006; Norberg et al., 2005; Ozono et al., 2007; Svavarsdóttir, 2005; von Essen et al., 2004), and former studies on mutual support groups (Coulson, 2005; Gooden & Winefield, 2007; Han & Belcher, 2001; Seale, 2006), as well as on the descriptive statistics of this study, mothers and fathers were treated as separate groups.

FINDINGS

Twenty-one parents, eleven mothers and ten fathers of 13 children answered the questionnaire at Time 1 of whom seventeen signed up to the CMSG listserv. Fifteen parents, eight mothers and seven fathers answered the questionnaires on the health related variables at all three times, and 13 parents, seven mothers and six fathers, answered the questionnaire on perceived mutual support at both post-test times.

All participants (N=21) were married or co-habiting. Most of them were 31 years of age or older ($n=16$), and had formal education beyond compulsory school ($n=12$). The majority resided in the capital area of Reykjavik ($n=12$), and worked outside the home ($n=19$). The majority of the children had been diagnosed at the age of five years or younger ($n=9$), two-to-six years prior to the study, with some sort of leukemia ($n=8$). All parents had computers and Internet access at home. None had participated in a CMSG before.

Health Related Outcomes of Parents

For mothers there was a statistically significant improvement in depression from Time 2 (mean score=.92, $SD=1.15$) to Time 3 (mean score=.63, $SD=.99$) ($p<.03$). Fathers showed statistically significant improvement in anxiety from Time 1 (mean score=.36, $SD=.10$) to Time 3 (mean score=.13, $SD=.11$) ($p<.01$), and in stress from Time 2 (mean

score=16.86, $SD=6.54$) to Time 3 (mean score=14.86, $SD=6.09$) ($p<.02$). For both mothers and fathers changes in somatization were seen from Time 1 and Time 2 to Time 3; however, these were statistically non-significant ($p\leq .05$).

At all three times, the mean scores for all four measures of mothers were higher than the scores of fathers. This difference was, however, statistically non-significant ($p\leq .05$). When detecting relationships between demographic and background variables, and the four health related variables at Time 1, tests indicated an inverse relationship between fathers' depression and education ($n=10$, $Rho=-.66$, $p<.04$), and an inverse relationship between mothers' anxiety and years since the child was diagnosed ($n=11$, $Rho=-.67$, $p<.03$).

Parents' Perceived Mutual Support

Parents' answers to the statements on perceived mutual support indicate that both mothers and fathers perceived mutual support to some extent from participating in the CMSG. Perceived helpfulness, altruism, instillation of hope, and universality were the strongest indicators of perceived mutual support for mothers. For fathers, instillation of hope, universality, perceived helpfulness, and group cohesion were the strongest indicators of perceived mutual support.

Indicators of perceived helpfulness were that mothers found writing their own messages helpful and both mothers and fathers found messages, suggestions and advice from others helpful. Mothers' believed that their messages helped others, and parents felt it important to try to assist others in the group, although this decreased for mothers from Time 2 to Time 3. Most parents perceived some instillation of hope when seeing that they were not alone with their problems and that others had adjusted to these problems. In

spite of perceiving universality to a large extent from participation in the group, as indicated by the feeling of “all being in the same boat”, it did not seem to help mothers to discuss feelings that they had previously had difficulties discussing. Fathers may have benefited more in this area. Parents’ answers to the statements on catharsis indicated a lack of it, although answers were mixed. Parents expressed discomfort with disclosing information about themselves over the computer. In some ways group cohesion was perceived by parents, especially mothers. They liked being members of this group and would participate in an other CMSG. Due to the small sample size and many parents stating that a number of the statements in the PMSS did not apply to them, no further attempt was made to detect changes in perceived mutual support from Time 2 to Time 3.

Parents’ Use of the Computer-Mediated Support Group

Parents were asked about how frequently they read messages and how frequently they wrote messages. Answers were received from 13 parents, seven mothers and six fathers. Mothers used the CMSG more than did fathers. Frequency of parents’ use of the CMSG decreased from Time 2 to Time 3. Most mothers used the CMSG for reading messages every day or at least once a week with little change from Time 2 to Time 3, but mothers’ writing of messages decreased from Time 2 to Time 3. At Time 2, fathers indicated that they read messages at least once a week or once a month, but less frequently at Time 3. Most fathers never wrote messages to the CMSG.

DISCUSSION

Study results indicate improvements in the health related outcomes of anxiety, depression, somatization, and stress of parents whose children have been diagnosed with cancer, while participating in a time-limited, unstructured CMSG. Both mothers and

fathers used the group and perceived mutual support to some extent from their participation.

The gender composition of the sample indicated that a CMSG may suit both genders equally. Participants came from both the Reykjavík area as well as from other parts of the country, indicating that a CMSG may be a good choice for parents residing far away from the health care facility or from other parents with a comparable experience. These results are in concordance with the results from Han & Belcher's study (2001), where the number of fathers' participating in a CMSG equaled mothers', and where parents who otherwise would not have been able to attend face-to-face support groups participated.

The mean scores for the health related variables indicated statistically significant improvement in mothers' depression and in fathers' anxiety and stress during the time of the CMSG. These results are clinically significant, supporting further studies on the development of CMSGs and participants' health related outcomes.

A gender difference was seen in the health related outcome scores; however, it was non-significant. These results are in concordance with a number of other studies on parents whose children have been diagnosed with cancer that have indicated higher scores of mothers' anxiety, depression, stress, psychosocial distress, and posttraumatic levels (Kazak et al., 2004, 2005; Lou, 2006; Norberg et al., 2005). This raises questions as to whether there actually is a gender difference in the well-being of mothers and fathers, or whether there is a difference in the sensitivity of the measurement tools for the genders. This needs further investigation. For the Dutch version of the SCL-90 the norms for men and women are different (Arrindell & Ettema, as cited in Wijnberg-Williams et al., 2006).

Mothers and fathers perceived mutual support to some extent from participating in the CMSG. The gender difference in perceived mutual support indicates a difference in perception of and expectation to group participation. Fathers may find it easier to talk about their fears and feelings within a group of other fathers with comparable experience in an only male group, than with their wives or other relatives (Neil-Urban & Jones, 2002). In spite of both genders primarily seeking information and emotional support from participating in CMSGs, differences in communication styles have been identified (Gooden & Winefield, 2007; Seale, 2006). Offering gender specific support groups may be of value.

In spite of liking to be a member of this group and wanting to participate in an other CMSG, participants were reluctant to express themselves freely about their experience and feelings. This may be due to the small population in Iceland, Icelandic culture and lack of tradition of support groups in Iceland. Icelandic parents may need more support or a structured intervention to feel comfortable in expressing themselves in a CMSG. Findings of former studies on mutual support groups indicated that participants in CMSGs needed more time to be comfortable with communication within the group than participants in face-to-face support groups (Walther, 1993; Walther & Burgoon, 1992).

Both mothers and fathers used the CMSG. However a gender difference was seen in use as well as change in use from Time 2 to Time 3. Mothers wrote and read messages, while fathers primarily read messages. Parents' use of the CMSG varied, which is in concordance with reported use in other studies on CMSGs, with some participants using the group more than others, and with a number of participants only reading messages (Han & Belcher, 2001; Radin, 2006; Winefield, 2006). With the anonymity and

asynchronous mode of CMSGs, participants can participate at their own pace and mode which seemed to suit the parents in this study.

A significant decrease was seen in parents' use of the CMSG from Time 2 to Time 3. This decrease in participation as well as parent' perceived mutual support indicate a need to better identify the appropriate structure and process of CMSGs for parents. Maybe a semi-structured group would have suited these parents better, with a pre-decided topic for each week and an educational component on that topic as well. Semi-structured CMSGs for caregivers of adult patients (Smyth, Rose, McClendon, & Lambrix, 2007) and semi-structured parental face-to-face mutual support groups (Foreman et al., 2005) have been shown to be of value.

Limitations

Several limitations are identified for this study, such as small sample size and the one-group before-and-after design. This matter is however difficult to change and may not be a serious one when kept in mind that the sample is a large part of the entire target population. In order to answer the question whether anxiety, depression, somatization and stress are valid health outcome measures for parental mutual support groups, further studies need to be done. The measurement tools used in this study had not been used for Icelandic parents before for a comparable purpose. Having no comparison group leaves the question unanswered whether the improvements in the health related outcomes were due to the CMSG intervention or not. The effective "dose" of intervention also remains unknown. The needed "dose" may vary between individuals. A "dose" of two months or even only reading two messages may be enough for someone, while a "dose" of four or six months or 100 messages may not be enough for others. The question whether the

parents who were in most need of mutual support participated in the study or not remains unanswered. All studies are at risk for selection bias of participants, but not least longitudinal studies with repeated measures, introducing a new way of health care provision with the use of technology. In spite of its limitations, however, the study is considered to have served its purpose, providing new knowledge on the feasibility of using computer technology in health care.

CONCLUSIONS

The results of this study support further development of CMSGs for parents whose children have been diagnosed with cancer. Further studies need to be done on the structure, process and outcomes of CMSGs, as well as on who may benefit from participation. For best results, a variety of research methods may be used, both qualitative and quantitative. Interviews with group participants may shed light on their expectations and needs, and observations and analysis of the structure and process of groups may shed light on the most effective way of providing mutual support groups.

Computer technology and its applicability to health care are global, but its enhancement and participants' approach to it may be culture related. In Iceland, as in many other countries of the world, use of computer technology and the Internet is general, providing opportunities for new ways of health care provision.

In spite of being conducted in a small country with a small sample, this study is considered timely and valid. No reports on comparable studies on CMSGs for parents whose children had been diagnosed with cancer were identified. The extent to which this study and its results can be applied to other populations and settings is questionable, as study results can never pertain to other populations, settings and times without being

tested. However, study results can be used to guide further development of CMSGs, whether for parents in Iceland or other populations in other settings and culture. Based on the results of this study the following suggestions are made as to how to strengthen a CMSG intervention for parents whose children have been diagnosed with cancer: a) screen for parental vulnerability factors such as anxiety, depression, and stress; b) include the CMSG intervention in the treatment regime; c) introduce the CMSG intervention to parents at diagnosis of the child; d) teach participants how to use the computer for the CMSG; e) provide a semi-structured group, where participants are required to participate actively; f) provide gender specific groups.

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