

Being a parent and coping with cancer: Intervention development

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ABSTRACT

Objective: Diagnosis of a parent's cancer has a profound influence on the parent, the children and the child–parent relationship, and puts all family members at risk for psychological distress. This article describes the development and the first attempts at implementation of an intervention aimed at helping people cope with difficulties arising from being both parents and cancer patients.

Methods: Based on themes discussed in focus groups with parents coping with cancer and with professionals in the field, a four-module psychological intervention was developed. The modules are: Telling and Sharing, Children's Responses, Routine and Changes, and Learning and Awareness as a Parent. The techniques used are mainly psycho-educational and cognitive–behavioral.

Results: Preliminary experience showed this intervention to be more feasible as a one-day workshop than as a four-session intervention. Parents who participated in two workshops reported it to be helpful in empowering them as parents and in imparting learning tools for identifying their children's needs, as well as for communicating with their children.

Significance of results: Intervention tailored specifically for parents coping with cancer can be relevant for their special needs. Research is needed to establish the effectiveness of this intervention.

KEYWORDS: Intervention, Parenting, Cancer, Children

Diagnosis of a parent's cancer in families with dependent children (< 18 years of age) has a profound influence on the ill parent, the healthy parent, and the child–parent relationship (Thastum et al., 2009). Diagnosis of a parent with cancer might put all family members at risk for psychological distress (Thastum et al., 2009).

People diagnosed with cancer are faced with unique, difficult challenges related to their parenting role. They struggle to preserve this role at a time of great personal need and distress. The ill parents' situation makes them care receivers, but their greatest concerns involve the simultaneous need to func-

tion as primary caregivers to their children (Fitch et al., 1999; Dunn & Steginga, 2000; Billhult & Segesten, 2003). Studies have shown that mothers with cancer reported trying to find a balance between being in need themselves and being strong for their children, as well as between the need to tell the children the truth and to protect them from it (Billhult & Segesten, 2003). In addition, mothers reported changes in relationships with their children, as well as struggling with communication issues (Fitch et al., 1999; Barns et al., 2000; Shands et al., 2000; Kennedy & Lloyd-Williams, 2009). Shands et al. (2000) found that mothers tended to give their children information and not focus on their emotions.

The children required even greater care at this time, as they were also in great need. Children of a parent with cancer were found to be at risk for experiencing anxiety, depression (Nelson & While, 2001),

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loneliness, helplessness, and guilt (Chirst et al., 1994). Some of the children tended not to express their concerns directly, but revealed them through their behavior and difficulties in school and with friends (Hilton & Elfert, 1996; Visser et al., 2004).

Among the factors that influence the children's adjustment to their parent's cancer are children's age and gender (Visser et al., 2004; Thastum et al., 2009) and the ill parent's gender (Thastum et al., 2009). Other factors include the ill parent's adjustment (Nelson et al., 1994, Nelson & While, 2001), difficulties in discussing the illness with the parent, having less time to be with friends and to spend on leisure activities (Nelson et al., 1994), the nature of parent-child relationship before the cancer (Chirst et al., 1994) and greater family responsibilities (Spira & Kenemore, 2000). Some of these are, at least in part, manageable by the parents and therefore highlight the parent's important role in the child's adjustment.

In the last two decades, a few efforts have been made to address these challenges within the family as a result of a parent's illness. Some of these efforts have taken the form of professional training, to help parents cope with parental issues (Turner et al., 2008), whereas others have taken the form of direct interventions for parents (Siegel et al., 1990), children (Bedway & Smith, 1996) or both (Lewis et al., 2006).

It is evident from the literature that most of the available interventions focused on the needs of parents with advanced-stage disease and focused mainly on communication. However, it seems that other sources of parent and child distress might exist, such as balancing between the parent's and the children's needs (Billhult & Segesten, 2003). Taking these into consideration, we developed a short-term intervention tailored specifically to parents coping with cancer, who are experiencing problems with their dual roles as parent and cancer patient. This article describes the development of this intervention, as well as its implementation challenges. The entire process of development and implementation was approved by the institutional ethical committee.

FIRST STAGE: RECOGNIZING THE NEEDS AND LEARNING FROM PROFESSIONALS AND PATIENTS

Two focus groups were conducted, to elicit major themes regarding parenthood and cancer. One group consisted of professionals (eight psychologist and social workers with experience in psycho-oncology) and the other consisted of parents in remission from cancer. The themes discussed in the professionals' group were: how to tell children about cancer, how to talk about genetic aspects, changes in family routine,

how to recognize a child in distress, the creation and use of support systems outside the family, and feelings of guilt and shame. The themes discussed in the parents' group were: how to talk about cancer with children, balancing between children's and parents' needs, balancing between keeping the family's routine and making room for the change, the use of support systems outside the family, the legitimacy of asking the children to help, to what extent to share feelings with the children, how to react when a child asks to see the surgery outcome, how to recognize a child in distress, and the variety of responses exhibited by children.

The themes that were discussed in both focus groups were organized into four categories by three independent judges, who specialized in psycho-oncology. The four categories were: Telling and Sharing (communication), Children's Responses, Routine and Changes, and Learning and Awareness as a Parent. In addition to these categories, the child's age and the family structure were found to be important in considering parents' and children's coping and adjustment. The four categories were used to create the four parts of the protocol.

SECOND STAGE: PROTOCOL DEVELOPMENT AND DESCRIPTION

Based on the four categories mentioned previously, we developed a psycho-educational cognitive-behavioral group intervention called "Being a Parent and Coping with Cancer (PCWC)." The main purpose of the intervention was to empower the patients and their spouses in their parenting role while facing cancer, and to help the parents help their children to adjust and cope. The group format was chosen because of the advantages of sharing and learning from each others' experiences. The intervention consisted of four meetings. Each meeting was devoted to another module according to the content categories that emerged through the focus groups and literature review. The four modules were:

- 1 **Telling and Sharing.** This module included discussion of communication issues; and emphasizing the importance of open and sincere communication, emotional exchange (sharing) and not just delivering the facts (talking), corresponding to the child's developmental stage and to cultural factors, and continuing communication.
- 2 **Children's Responses.** This module included a discussion about the diversity of children's responses and reactions to the parent's cancer and different variables influencing the

responses (e.g., the child's gender, age, birth order, family role, and former relationship with the ill parent). Emphasis was placed on the variety of expressions of emotions and the continuum between normative responses and those that demand special attention and intervention.

- 3 Routine and Changes. This module included discussion of the challenge of maintaining a balance between the family's routine and making room for the changes imposed by the illness and treatment. This included issues of boundaries, compensation, using the support from family members and friends, preserving intimate time with the family, as well as maintaining constant rules and routines.
- 4 Learning and Awareness as a Parent. This module summarized the process the parent underwent during the intervention, including reflecting on what they learned about themselves, their children, and their family.

The participants received a workbook specifically developed for the group intervention. The workbook was designed as a tool that each parent can keep, and includes information, space to write thoughts or personal comments, exercises completed in the group, and homework for each module. In addition, it includes an appendix that describes children's age-appropriate reactions to a parent's illness, based on Hamilton's review (2001).

THIRD STAGE: PILOT INTERVENTION IMPLEMENTATION

Patients who were also parents, and who were undergoing chemotherapy at the daycare unit at Hadassah University Hospital in Jerusalem, were invited to participate in the proposed intervention. Only a few patients accepted the invitation. Although they appeared to be very interested in the subject, they seemed overwhelmed by the cancer diagnosis and treatments and had difficulty committing to four intervention sessions between their daily visits to the oncology clinic.

In light of this, we offered patients a one-day workshop that included the first three parts of the intervention (implementing the fourth module requires prospective reflection on the participation in the intervention process and was not relevant to a one-day workshop). We conducted two workshops for parents. One was conducted at the clinic of the Israel Cancer Association and one at the Community Psychological Services Clinic of Bar-Ilan University. Participants were invited to both workshops via a

newspaper advertisement and flyer distribution in psycho-oncology units in cities close to the clinics.

Ten parents participated in each workshop. The first group consisted of seven women and three men. All women were patients, two men were spouses and one man was the brother of a patient who was a single parent. The second workshop consisted of eight women and two men. One man was a spouse and one was a patient, and three women were spouses. Although the workshop was originally designed for parents coping with initial disease stages, the attending participants varied in the type and stage of their cancer. Children's ages ranged between a few months and 17 years, and the number of children per family ranged between one and six.

To receive a preliminary impression about the intervention's effectiveness, we asked participants in the group for their feedback. We asked why they had decided to participate in the intervention, in what way they perceived it to be helpful, and whether they perceived the intervention, or parts of it, as unpleasant or disturbing. The most common reasons reported for participating were the need to reinforce their chosen coping strategy, the need to ask questions regarding their children's responses and adjustment processes, and their difficulties in communicating with the children. All participants reported benefiting from the intervention, and none reported any negative aspects. For some, the intervention reinforced the way they had chosen to cope and to support their children, and made them feel good about their parental role and function during the cancer experience. For others, the intervention helped to clarify issues and to improve their understanding of their children's responses to the cancer and their relationships with them.

In addition, all the participants noted the group format as one of the intervention's positive components. Mutual sharing and learning was important. In both groups, the participants reported that the heterogeneity in gender, role (patient/spouse), and cancer stage was a positive factor in the intervention. Surprisingly, parents in different phases of illness trajectory were coping with similar questions regarding their children. Moreover, parents in early stages of the illness did not report being intimidated by meeting parents with advanced cancer. Participants reported heterogeneity as a positive aspect in that it enabled different points of view and enriched the discussions.

SUMMARY

The PCWC intervention was developed based on clinical impressions and literature, and through discussing the special needs of parents and children

copied with the parent's cancer. A broader view of these needs that goes beyond communication issues was adopted and specific modules were constructed as a result of two focus groups. The modules were Telling and Sharing, Children's Responses, Routine and Changes, and Awareness and Learning as a Parent.

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