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Resourcing: An approach used by foreign-born parents struggling on in childhood cancer care

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ABSTRACT

Purpose: To gain knowledge about foreign-born parents' experiences of dealing with their child's illness and treatment in the context of pediatric cancer care.
Method: Data from 11 individual interviews with foreign-born parents were analyzed using qualitative inductive constant comparative analysis.
Results: To struggle on in childhood cancer care, foreign-born parents engaged in resourcing using various strategies including: information-monitoring, staying strong, support-seeking and concern-focusing. Parents experienced obstacles to information-monitoring and support-seeking related to their foreign background.
Conclusions: The results provide a framework for understanding how foreign-born parents try to deal with childhood cancer care and can be used by health care staff to support their resourcing. Even though preconditions might differ, the strategies presented might also be used by native-born parents however further studied are needed.

1. Introduction

Childhood cancer is considered a potentially life threatening and serious life event that alters the entire family's life situation (Pai et al., 2007). Family life is disrupted (Bjork et al., 2009), including a loss of control and security (Bjork et al., 2005) and "is never the same" (Woodgate, 2006, p.8). The experience has been described as "getting through all the rough spots" (Woodgate and Degner, 2003, p.108) and "a broken life world" (Bjork et al., 2005, p.269). According to the literature parents are "trying to cope" (Enskar et al., 1997, p.160) with a complex life situation and a long period of psychosocial distress and uncertainty (Boman et al., 2003; Norberg et al., 2005). The first year after diagnosis parents of children with cancer report a significantly higher level of distress than parents of healthy children (Pai et al., 2007). In Sweden the level of stress after completion of treatment has been found to be higher among foreign-born parents than native-born parents (Norberg et al., 2005).

In 2013, persons with a foreign background made up about 21% of the Swedish population (Statistics Sweden, 2013a) and Sweden had foreign-born persons from about 200 countries (Statistics Sweden, 2013b). Residence permits were predominantly granted on the grounds of family ties (Swedish Migration Board, 2013a), with the largest group during 2006–2011 coming from Iraq (Swedish Migration Board, 2013b). Immigrants from non-European countries report that they suffer from poor health three to four times more often than Swedish born people (Hjern, 2012). Refugees are predisposed to poor psychiatric health (Hjern, 2012), and previous traumatic experiences, rather than immigrant status, predispose parents for posttraumatic stress symptoms when their child has been diagnosed with cancer (Boman et al., 2013). Sweden is a relatively segregated country in the sense that people coming from non-Western and non-European refugee countries are marginalized, tend to live in the same neighborhoods and have low employment rates (Lofors et al., 2006; Sundquist and Johansson, 1997). However, because health care in Sweden is publicly funded, families with a foreign background are commonplace in Swedish health care, including childhood cancer care.

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Not much research has been done with this group in pediatric cancer care because foreign-born parents comprise a heterogeneous group that is often excluded from research because of language difficulties, as evident in the studies from Swedish pediatric cancer care reviewed above (Bjork et al., 2005; Boman et al., 2003; Enskar et al., 1997; Norberg et al., 2005). In a Canadian study, immigrant parents of children with cancer have reported that they suffered from sleep disturbances, anxiety and depression (Klassen et al., 2012a). Challenges included: accessing support, financial pressures, caregiving demands and interactions with the health care system (Klassen et al., 2012b). A previous study from Swedish childhood cancer care presents how foreign-born parents are protecting family interest in care using different approaches to interaction with health care professionals (Pergert et al., 2012). In the same study, parents experienced powerless-dependence because they were dependent on health care staff for information and care (Pergert et al., 2012). Research is needed on how foreign-born parents deal with their child's illness and treatment in the context of pediatric cancer care.

The purpose of this study was to gain knowledge about foreign-born parents' experiences of dealing with their child's illness and treatment in the context of pediatric cancer care.

2. Methods

2.1. Sample and participants

Intensive treatment for children with cancer is provided at 6 publicly funded regional childhood cancer centers in Sweden. The sample of parents was, for reasons of convenience, taken from one childhood cancer center at a university hospital in Sweden. Potential participants were identified by the first author through a list of newly diagnosed patients and by a care coordination nurse. Criteria for eligibility were:

1. the parent was foreign-born and had been present at the hospital during the child's admissions,
2. at least 3 months had passed since the diagnosis,
3. the child was still undergoing treatment at the childhood cancer care unit.

Three months since diagnosis meant that these parents had some experience of dealing with their child's illness and treatment. Three parents declined to participate in the study; one because she did not identify herself as a person with a foreign background; one because he was already included in another qualitative study and one mother wanted to participate but was unable to be interviewed because of her child care commitments.

The participants included 11 parents (10 mothers, 1 father, $M_{\mathrm{age}} = 40$ years, age range: 26–47). Six parents stated that they had more than 13 years of education and two parents stated less than 9 years. The time since immigration varied ($M = 6$ years, range: 2–18 years) and the self-reported reasons for immigration included family reunification ($n = 8$), labor market ($n = 1$), refugee ($n = 1$) and adventure ($n = 1$). Continents of origin included Greater Middle East ($n = 6$) Europe ($n = 4$) and South America ($n = 1$). Five of the parents had Arabic as their mother language. For more information on the participants, see Table 1. The participants' children ($M_{\mathrm{age}} = 8$ years, age range: 2.5–16) had the diagnoses of leukemia ($n = 5$), brain tumor ($n = 1$) and solid tumor ($n = 4$); both parents of one of the children participated separately. The time that had passed from diagnosis to the time of the interview ranged from 4 to 26 months, with a median of 10 months.

2.2. Ethical issues

The study was approved by the Regional Ethical Review Board. Potential participants were invited to participate by a care coordination nurse, who was not involved either in the patients' direct care or in the research project. She explained the purpose of the study verbally, and this was reinforced by an information sheet available in Swedish and Arabic. Translation to other languages was also offered, but was never needed. Parents who consented verbally to participate were contacted by the first author to make an appointment for the interview. Confidentiality, the voluntary nature of participation and the right to withdraw at any time were emphasized before the interviews. Willingness to be interviewed was accepted as consent.

2.3. Data collection

Eleven individual interviews were carried out by the first author and lasted from 30 to 150 min, with a median of 70 min. The interviews were planned during one of the visits of participants to the out or in-patient department during their child's treatment for cancer. All interviews were carried out in a private room in the children's hospital. The technique of “open-ended conversations” (Glaser and Strauss, 1967, p. 75) was employed using an interview guide which included a list of potential questions about experiences of the child's illness and treatment. Examples of enquiries were: 1) Please tell me about when your child first became ill, and 2) Please tell me about your experiences of the child's illness and treatment. The interview guide and a questionnaire with sociodemographic characteristics were translated into Arabic by an independent authorized translator, thereafter it was back translated by an interpreter and the two versions were compared.

All interviews were conducted in Swedish, the native language of the interviewer. All participants were given the opportunity to use an interpreter in their native language, but the majority (7/11) preferred to converse in the Swedish language. Four participants, all Arabic speaking, opted to use an interpreter and the same woman, an authorized health care interpreter, was used on each occasion. Triangular seating (Phelan and Parkman, 1995) and consecutive translation were used and rather than matching for gender, culture and religion, one and the same interpreter who was well informed about the research process was used, which is in accordance with the literature (Abbe et al., 2006; Wallin and Ahlstrom, 2006). All interviews were sound recorded and field notes were written immediately after each interview.

Data was collected and analyzed concurrently and this process influenced what data was collected next, in that questions were added in the end of subsequent interviews. The sample size was determined by the saturation of core and sub-core categories (Glaser, 1998). Categories were judged to have reached saturation when the same information about the categories appeared repeatedly in the data (Glaser, 1978).

2.4. Data analysis

The first author transcribed the data verbatim in Swedish. The software program NVivo (QSR International, 2002) was used as a coding tool. The second author listened to the recordings independently, read transcripts and field notes, and discussed emerging categories with the first author. Open inductive coding, using in-vivo codes, was used until the core and related categories had emerged, whereupon selective coding was conducted using more conceptual codes. Incidents, codes and categories were constantly compared (Glaser, 1978, 1998; Glaser and Strauss, 1967). Multiple interchangeable reoccurring incidents were required for each