



Family Functioning as a Constituent Aspect of a Child's Chronic Illness



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This study explored how family functioning may contribute to trace a child's illness trajectory. We conducted semi-structured interviews with 33 parents of children in care at a hospice in northern Italy. We also examined the medical records of the children, and interviewed the physician who cared for them. Data analysis was based on the grounded theory approach. Different illness progressions corresponded to the different ways with which families experienced the illness: possibility, focus on illness, denial, and anger. Clinical interventions should involve the whole family and take into account their role in the construction of illness trajectories.

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IMPROVING MEDICAL CARE has expanded the lifespan of children with progressive, life-threatening illnesses. In Italy, approximately three million children live with chronic health conditions (Italian Pediatric Society, 2012). Many of these children survive for long periods with complex chronic conditions, characterized by the progression of the illness to a point that requires specialized and time-consuming care. The terminal phase, however, may be months or even years away. The continuous care required by these conditions implies an enormous engagement by families and health systems. Hospices were created to assist children and their families, but the recent trend toward home care increases the involvement of the families.

Many studies have focused on the impact of the child's illness on the family (Hopia, Paavilainen, & Paivi, 2005; Katz, 2002; Moola, 2012) and on the adaptation process and coping strategies families use (Garro, 2004; LaMontagne, Hepworth, Salisbury, & Riley, 2003). In contrast, few studies have explored the influence of family on an individual's response to illness (Knafl & Gilliss, 2002). In this

introduction we present only the literature in this area because the aim of our study was to explore how family functioning may contribute to the development, maintenance, and progression of the child's illness.

The Family as Producer of Health and Illness

In the Family Systems Illness Model, Rolland (1987) emphasized the intertwining of two evolutionary threads: the illness and the individual family life cycles. Referring to the three major disease phases (i.e. crisis, chronic, and terminal), he outlined an understanding of the ever-changing needs and requirements of the patient, the couple, and the family system over the course of the family life cycle.

Patterson, McCubbin, and Warwick (1990) found that parents' involvement in activities that enhanced self-esteem helped manage psychological tension, and provided social support benefits for the health of a child with cystic fibrosis. Wong and Heriot (2008) pointed out that the hope and despair parents had for the future of their child and parental coping styles were important predictors of parent and child adjustment. Other studies heightened that greater family cohesion and less family conflict were linked to better adjustment in children with chronic illness (Mitchell et al.,

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2007; Perrin, Ayoub, & Willet, 1993; Thompson et al., 1999). By contrast, less cohesiveness and expressiveness and more control in families were associated with internalizing behavioral symptoms (e.g., anxiety and depression). Greater family conflict and less encouragement of independence were associated with externalizing behavioral symptoms (e.g., acting out behaviors) (Morris et al., 1997).

In addition, family roles, communication, and effective responsiveness were indicated as involved in predicting child behavioral functioning. Caregivers who did not involve children in family responsibilities and who treated their children as more vulnerable may have led these children to experience more difficulties with internalizing behaviors. Alternatively, these children may have been perceived as less likely to complete responsibilities because of symptoms related to internalizing behaviors. Family communication also influenced internalizing behaviors, but again the direction was not clear: poor family communication may have led children to be more reserved, or vice-versa (Piazza-Waggoner, Adams, Muchant, Wilson, & Hogan, 2006).

The main limitation of these studies was they observed correlations between family factors (usually assessed by the Family Environment Scale) and the child's psychosocial adjustment (variously assessed by different behavior problem checklists or social competence scales). This prevented an understanding of the process leading to this association. Such a comprehension would offer useful indicators to build an effective clinical intervention with these families.

In our study, we explored how family functioning and the way of living with a child's chronic illness may influence the illness trajectory. A trajectory is defined as the course of the illness over time from the perspective of the ill person and the carers (Glaser & Strauss, 1968). By involving both parents of the ill child, we wanted to understand illness trajectories in relation to the ways parents related to each other and to their children, and to the family story and organization. We considered different chronic illnesses instead of focusing exclusively on cancer, because so much research has analyzed the experience of parents of a child with cancer (Bjork, Nordstrom, Wiebe, & Hallstrom, 2011; Earle, Davies, Greenfield, Ross, & Eiser, 2005). By contrast, research on other chronic illnesses has been less expansive or has focused on a single chronic illness, thus preventing a comparison of the experiences of families coping with different illnesses. Patterson, Holm, and Gurney (2004) found that most of the strains, resources, and coping behaviors of the parents of a child ill with cancer were similar to those described in studies of families experiencing other childhood chronic conditions, thereby allowing us to overcome this distinction and focus on how family organization may impact on illness trajectory.

Method

Participants

We recruited thirty-three parents (twenty mothers and thirteen fathers, aged between 30 and 55) of children with

progressive chronic illnesses at a pediatric hospice in Padua, Italy as study participants. The affected children (twelve males and eight females) ranged in age from 3 months to 18 years, and all lived at home. They were diagnosed with different progressive chronic illnesses, and were all indicated for palliative care. Five children had central hypoventilation syndrome (CCHS), one CHARGE syndrome, two Menkes syndrome, one Duchenne muscular dystrophy, one central core disease (CCD), five spinal muscular atrophy (SMA), two brain tumors, one spinal dysraphism, one transverse myelitis, and one Down syndrome. The final number of participants was not predetermined. Our sampling ended once we considered the theoretical saturation had been reached, that is the point at which gathering more data yields no further theoretical insights about the emerging theory (Charmaz, 2006).

The university ethics committee approved the study. The chief of the hospice mediated contact. We met physicians, nurses, and psychologists who provided care to the children and interviewed one of the pediatricians, a 58-year-old woman. Each day, for a period of 4 months, one of us went to the hospice and collected data on the experiences of the families. There, a nurse or a psychologist of the ward introduced the study and the researcher to the families and obtained written informed consent. One mother among those who were asked refused to participate in the study, as did seven fathers whose wives participated in the study: Four were not interested, two were not available, and the last was unable to agree on a date.

Data Collection

We developed a semi-structured interview guide based on our review of the literature on parenting children with chronic illnesses. After a brief general introduction to the interview, participants usually spontaneously began to tell their experiences; otherwise, the interviewer began with a broad question about the parents' experiences with their child's illness and went on to explore various topics (e.g. when it was diagnosed, how parents reacted, their relationship with health care system, family roles and history).

Most of the interviews were conducted at the pediatric hospice. Our goal was to gather the experiences of both parents individually, but they were not always both present at the hospice, so we conducted a minor part of the interviews at participants' homes.

We also examined the medical records of the chronically ill children, and interviewed the physician who provided care to the children in order to obtain data pertaining to their clinical conditions, illness progression, family situation and relationship with the health care professionals from the physician's point of view. The interviews lasted from 40 minutes to 2 hours. They were audio-taped and transcribed verbatim. We used pseudonyms to indicate children.

Data Analysis

The analysis of the interviews was guided by the principles of grounded theory (Strauss & Corbin, 1998).

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