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Parental Perceptions of the Outcome and Meaning of Normalization

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Abstract

The purpose of this secondary analysis was to identify the meaning of normalization for parents of a child with a chronic genetic condition. The sample was comprised of 28 families (48 parents), selected to reflect two groups: Normalization Present (NP) and Normalization Absent (NA). Constant comparison analysis was used to identify themes characterizing parents' perceptions of the meaning of normalization. The meanings parents attributed to normalization reflected their evaluation of condition management, parenting role, and condition impact, with parents in the NP and NA groups demonstrating distinct patterns of meaning. These meaning patterns are discussed as an outcome of normalization. Providers can play a pivotal role in helping families achieve normalization by providing guidance on how to balance condition management with normal family life.

Keywords

family; genetic condition; normalization

The concept of normalization has received considerable attention in the literature on family response to childhood chronic illness. Researchers studying varied chronic conditions have found that parents consistently identify normalization as a valued goal and develop strategies to create and sustain a family life they experience as normal and satisfying. The complex concept of normalization is both a process and an outcome, and these two aspects of the concept may overlap and often are not differentiated precisely in the literature (Deatrick, Knafl, & Murphy-Moore, 1999; Gjengedal, Rustoen, Wahl, & Hanesta, 2003; McDougal, 2002; Rehm & Bradley, 2005; Robinson, 1996). Normalization entails the efforts family members make to create a normal family life (process), their perceptions of the consequences of these efforts (outcome), and the meanings they attribute to their management efforts. Many researchers on normalization have focused on the process dimension and the identification of parental strategies for creating a normal family life.

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Although researchers have established that parents view normalization as a positive response to managing a child's chronic condition (Deatrick, Knafel, & Murphy-Moore, 1999; Robinson, 1996) comparatively little is known about parents' perceptions of the meaning and consequences of normalization (or lack thereof) for family life. The purpose of this study was to identify the meanings parents attribute to a family life characterized by either the presence or absence of normalization based on an analysis of data from two groups of parents (those who achieved normalization and those who did not).

The literature on normalization includes integrative reviews aimed at conceptual clarification and research on the nature and scope of normalization in families with children having varied chronic conditions. In their review of 33 articles reflecting 14 studies published between 1966 and 1997, Deatrick et al. (1999) identified five attributes of normalization: acknowledgment of the condition and the potential to threaten lifestyle; adoption of a normalcy lens for viewing the child with the condition and the family; engagement in parenting behaviors and family routines that are consistent with a normalcy lens; development of a treatment regimen consistent with a normalcy lens; and interaction with others based on a view of the child and family as normal. The first two attributes reflect parents' definition of the condition as serious and its potential to disrupt family life, as well as their deliberate decision to adopt a normalcy lens for viewing their child and family (Robinson, 1993). Parents who adopt this lens emphasize the normal aspects of their lives and the many ways family life remains unchanged despite the child's condition. Over time, these parents learn that condition management does not have to be the focus of family life. Robinson (1993) speculated that normalization is grounded in a fundamental culturally based "belief in the importance or goodness of living life as normal" (p. 12). The three remaining attributes identified by Deatrick et al. are focused on the process of normalization and the kinds of management and interactional strategies parents adopt to sustain a normal life.

Morse, Wilson, and Penrod (2000) further refined the concept of normalization through observations of 17 children with severe, chronic physical disabilities during a 6-day summer camp and through telephone interviews with their mothers. Important to the process of normalization were reference groups; both mothers and children identified with two social reference groups that these investigators termed *disabled as normal* and *everyday as normal*. Also focusing on the process of normalization, these authors described strategies mothers and children used to foster their access and fit with both groups, factors influencing identification with one or the other group, and barriers to integration with each group. In addition, they discussed the implications of their results for the attributes of normalization identified in the review by Deatrick et al. (1999).

Although most families in which there is a child with a chronic condition achieve normalization, there is evidence that not all families, even some who view normalization as desirable, are able to normalize family life. For example, Rehm and Bradley (2005), in their studies of families of technology-dependent, medically fragile, developmentally delayed children, found that over time parents relinquished the goal of having a family life that was similar to that of families without a severely disabled child, accepted the need of organizing family life around the care of their child with special needs, and developed strategies to assure the family's and the child's social safety and comfort. These parents described their lives as being good without being normal. The importance of normalization as a frame of reference also was evident in Gantt's (2002) study of mothers and their daughters with congenital heart disease. Gantt found that all subjects (11 daughters and 11 mothers) "when asked about the influence of heart disease on their lives and relationships most frequently replied whether their lives were normal or not" (p. 484). It is clear that normalization

remains an important reference point for parents, against which they assess the adequacy and focus of their efforts to manage their child's chronic condition.

The goal of this secondary analysis was to examine parents' perceptions of normalization and the meanings they attributed to the presence or absence of normalization for family life. An additional goal was to explore differences in perceptions between parents who described their family life as normal and those who did not. The study was guided by Park and Folkman's (1997) definition of meaning as "perceptions of significance" (p. 116) and was based on the assumption that a more precise delineation of meaning would serve to clarify further what parents believed were the outcomes of normalization for family life.

Method

Data for this analysis were taken from a subsample of 86 families who participated in a larger study of families who had a child with a genetically based chronic condition (parents' Interpretation and Use of Genetic Information, R01HG/HD02036, P.I. Gallo). An overview of the larger study is presented as the context for the sample and procedures used in this secondary analysis.

Overview of parents' Interpretation and Use of Genetic Information

The overall aim of the larger study was to identify patterns of family information management with regard to a child's condition. The study was based on the Family Management Style Framework (FMSF), which was used to conceptualize parents' perceptions of key aspects of family response to childhood chronic conditions, including parents' definition of the situation, management efforts, and assessment of the consequences of the condition for family life (Knafl, Breitmayer, Gallo, & Zoeller, 1996; Knafl & Deatrick, 2003). The FMSF is used to assess what family members do to incorporate condition management into everyday life, including the meanings they attach to their management efforts and their perceptions of the impact of the condition on family life. The sample design was noncategorical. Families were included in which children had varied conditions (phenylketonuria [PKU], sickle cell disease [SCD], cystic fibrosis [CF], neurofibromatosis [NF], Marfan's syndrome, thalassemia, hemophilia, and von Willebrand Disease) and that met the following inclusion criteria: single-gene condition; child 3-15 years of age; biological offspring of at least one parent living in same household as child; and regular school attendance.

Following institutional review board approval at all sites, parents were recruited from three outpatient specialty clinics that served urban and suburban children with genetic conditions in a large Midwestern metropolitan area. Parents were contacted about participation via a letter from the clinic director or in person by a member of the research team. Both parents in two-parent families were invited to participate. Parents signed an informed consent form prior to participating in a single, individual semistructured interview about their needs for and use of information related to their child's condition. Although the focus of the larger study was how parents accessed, interpreted, and used genetic information, additional contextual data were gathered about their daily management of the child's condition and their perceptions of their child and family life.

In addition, parents completed two standardized measures of family functioning, the Family Adaptability, Partnership, Growth, Affection, and Resolve (APGAR) rating system (Austin & Huberty, 1989; Smilkstein, 1978) and the Family Hardiness Index (FHI; McCubbin & Thompson, 1991; McCubbin, Thompson, & McCubbin, 1996). The Family APGAR is a 5-item instrument designed to measure family members' satisfaction with family life. Item scores range from 0-4, with overall scores from 0-20. Higher scores indicate better family

satisfaction. The FHI is used to measure the internal strengths and durability of the family and is comprised of 20 items rated from 0-3, producing an overall score between 0-60. Higher scores indicate a greater degree of family hardiness. Strong reliability and validity has been reported for both measures (Sawin & Harrigan, 1995), and their internal consistency reliability in this study was .86 for the APGAR and .81 for the FHI.

The data management and analytic methods used in the larger study included verbatim transcription of interviews, coding of all interview data, and completion of narrative summaries. To assure data quality, transcribed interviews were reviewed for accuracy against the original tape-recorded interview. Further efforts to enhance quality included coding of the first 94 transcripts (71%) by two members of the research team who met to resolve any coding discrepancies. When it became evident that members of the team were consistent in their application of codes, the final 39 transcripts (29%) were coded by one team member. Data coding and retrieval were facilitated using ATLAS.ti (ATLAS.ti GmbH, Berlin, Germany). In particular, ATLAS.ti was used to contribute to the comprehensive review of all relevant data on selected topics during the course of data analysis.

To complete interview summaries, the three major components of the FMSF (definition of the situation, management behaviors, and perceptions of consequences) were used to structure two summary templates for each interview: one was focused on parents' management of genetic information and one focused on the contextual data related to overall family response to having a child with a genetic condition. Analyses entailed review of written case summaries and coded data. The results of the larger study have been reported elsewhere (Gallo, Angst, Knafel, Hadley, & Smith, 2005; Gallo, Hadley, Angst, Knafel, & Smith, 2008; Gallo, Knafel, & Angst, 2009; Knafel, Knafel, Gallo, & Angst, 2007).

Secondary Analysis

Although the larger study was focused on parents' management of genetic information, interview questions related to daily management of the child's condition and perceptions of family life yielded detailed accounts of families' everyday lives. Parents talked about what they did to manage the condition and the meanings they attributed to their management efforts. Although parents were not asked directly about normalization, their responses to queries about how the child's condition and its management influenced family life were detailed and couched in terms of the presence or absence of normalcy in their lives. These information-rich data provided an opportunity to carry out the analysis reported in this manuscript.

Sample—This analysis was based on data from 28 of the 86 families in the original study. Parents were selected purposively based on the principle of intensity sampling, which entails the selection of cases that are information-rich relative to the phenomenon of interest (Patton, 2002). In the present analysis, the goal was to select families who intensely reflected the presence or absence of normalization, because it was believed parents' perceptions of meaning would be particularly evident in these cases. Lacking a direct measure of normalization, sample selection was guided by Deatrick et al.'s (1999) conceptualization of normalization and was focused on the identification of families for whom the data were indicative of the presence or absence of normalization.

The study team used a number of sources of evidence to select the intensity sample, including parents' narrative accounts of family life as reflected in their case summaries and scores on the FHI and Family APGAR. The first two authors individually reviewed the interview summaries of contextual data related to overall family life and reached consensus on parents who minimized the consequences of the condition and emphasized normalcy and ease of condition management versus parents who expressed the opposite. The results of a

prior cluster analysis also were used to identify parents who scored relatively high or low for the sample on the two measures of family functioning (Knafl et al., 2007). In addition, cases were selected to assure variation in diagnosis and family structure in the final sample. In families where two parents participated, a consistent pattern of ease or difficulty had to be detected in data from both parents based on the interview summaries and scores on the standardized measures. The second two authors provided input on the sample selection process and the appropriateness of the final sample.

The final intensity sample included 28 families (48 parents). Eighteen families (30 parents) represented intense instances of normalization (Normalization Present; NP), and 10 families (18 parents) represented intense instances of the absence of normalization (Normalization Absent; NA). The parents in this subsample were diverse in family structure and diagnosis. Parents of children with the following diagnoses were included: PKU, NF, CF, SCD, thalassemia, hemophilia, and Marfan's syndrome. The NA group did not include the parent of a child with hemophilia, but all other conditions were represented in both groups. The children ranged in age from 3 to 15 years. There were 14 boys and 14 girls, although they were not distributed evenly in the two groups: the NP group had 11 girls and 7 boys; the NA group had 3 girls and 7 boys. There were 6 single-parent families in the NP group and 2 in the NA group.

Analysis—Following sample selection, the first two authors again reviewed the interview summary for each parent and data from coding categories that were relevant to the attributes of normalization: family illness management, view of child, view of condition, and impact of condition on family life. The analysis was guided by the principles of constant comparison (Glaser & Strauss, 1967) and supported by the use of matrices to display data in a way that assured systematic comparison (Miles & Huberman, 1994). A series of descriptive and analytic matrices were created by the first two authors and reviewed and validated by the other authors. Descriptive matrices were used to summarize the data from selected codes and to facilitate the identification of themes reflecting the meaning parents attributed to how they incorporated condition management into everyday family life. Based on a review of the descriptive grids, three major themes (perceptions of condition management, parenting role, and impact of the condition) were identified and summarized on two analytic grids, one for families in the NP group and one for families the NA group. The analysis revealed distinct patterns of meaning for parents in the two groups regarding their evaluation of management of the child's condition and parenting efforts and their assessment of the impact of the condition on family life. Following an analysis of how the themes were manifested by each group, the NP and NA groups were compared to identify similarities and differences in the meaning parents attributed to their condition management, parenting, and family life.

Results

Distinct differences were revealed in the meaning parents in the NP and NA groups attributed to their everyday management of the condition, their parental role, and the impact of the chronic condition on their family life. For parents in the NP group, normalization signified competence in managing the condition and incorporating management into daily family life. Normalization meant they were adapting successfully to the challenges of having a child with a chronic condition and were competent in their parenting role. It was linked also to perceptions of positive outcomes of having a child with a chronic condition, which provided further evidence of successful adaptation and parenting.

For parents in the NA group, the absence of normalization signified the difficult and atypical nature of their lives and their shortcomings as parents. These parents believed that the effort

required to manage the treatment regimen necessitated that it be the focus of family life. Parents in this group pointed to the multiple negative consequences of the child's condition as further evidence of the difficult, unusual nature of their family life and the negative impact of the condition on their lives.

Family Management of the Condition

Doing a good job (NP group)—Parents in this group spontaneously compared themselves to families of healthy children and described their perception that they were leading a normal family life as evidence of successful family management. Their interviews were filled with accounts of what parents, children, and the whole family were doing right. For example the mother of a daughter with PKU said:

The fact is that it is a routine, something we have adapted to. I mean we have reached a degree of normalcy. Where maybe it's not the same kind of routine that everyone else follows, but it's our routine. PKU can be adapted to a regular life and activities.

For these parents, normalization signified successful family management.

Parents' accounts of their approaches to condition management were presented as evidence of their success in maintaining an appropriate balance between condition management and other aspects of family life. Maintaining an appropriate balance meant that the child's condition usually was not the focus of family life. For example, the mother of a child with CF described her efforts to balance “fixating on it, which is wrong, and ignoring it, which is wrong too.” She went on to describe CF as “something that everybody just lives with around here. We sit down at the dinner table, and we've got the salt and the pepper, and the enzymes.” Families in the NP group had integrated the treatment regimen into the usual family routine, and their ability to do so was described in positive terms. Normalization meant they were doing a good job of taking care of the condition without making it the constant focus of family life.

At the same time, parents acknowledged that occasionally when there was a crisis or exacerbation related to the child's condition, it was appropriate for family life to center on the ill child and for the usual routine to be interrupted. However, occasionally focusing on the condition was described as temporary and not a threat to successful adaptation.

Parents also described how condition management had become easier and less time-consuming over time since diagnosis. They described progress over the years in being able to do a good job of minimizing the disruptive aspects of condition management. They recognized that they had become more competent in carrying out the treatment regimen, interacting with health care professionals, and balancing condition management and other aspects of family life, all of which contributed to their sense of normalcy and belief they were doing a good job of successfully adapting. The father of a daughter with PKU contrasted the “early years when we went overboard in terms of measuring food amounts” to the family's current, more streamlined approach to condition management, stating, “We were spending tremendous amounts of time making the formula every day; now we make a batch of formula for 8 days.” For these families, normalization signified progress. They had moved from focusing on the condition to balancing condition management with other aspects of family life.

Living a difficult life (NA group)—Unlike parents in the NP group, parents in the NA group did not discuss their management efforts in terms of success, failure, or doing a good job. Rather, they described themselves as managing the only way they thought possible to assure reasonable control of their child's condition. The father of a child with CF said:

It affects us quite a bit. You can't have much of a social life. It is constant caretaking. It is a constant deal, 24 hours a day, 7 days a week. There are no breaks in it. Nothing makes it easier. It's hard on everybody, but we do it, and it's just what we have to do. It's part of living with a child that has a critical illness.

In a similar vein, the mother of a child with CF described family life in the context of her child's condition, saying:

You think about what you go through every day, the struggles. It's hard at times, and sometimes people look at you and think you make it seem harder than it is. It doesn't seem like a big deal to them, but it is. They don't go through it every single day.

Parents in the NA group believed that condition management had to be the focus of family life because of the time and effort involved. They explicitly linked condition management to their inability to lead what they considered to be a normal family life. For them, the absence of normalization signified their daily life was more difficult than that of other families.

Similar to parents in the NP group, parents in the NA group typically took pride in their competency in carrying out the treatment regimen. Nonetheless, they believed that an inevitable outcome of competent management was that family life had to revolve around the condition. The focus on condition management was a constant reminder to parents of the difficulty of their situation. For example, the mother of a child with PKU who had described PKU management as a “nightmare that consumes the day” went on to say, “But I guess we've been doing a good job (of controlling the condition) because the (phenylalanine) levels have stayed where they are supposed to be.” Unlike parents in the NP group, who discussed their management goals in terms of maintaining an appropriate balance between adhering to the treatment regimen and other aspects of family life, parents in the NA group emphasized strict adherence to the treatment regimen and described the difficulties faced in their efforts to achieve full adherence. Parents in the NA group, in contrast to those in the NP group, did not describe condition management as becoming less difficult over time. Although NA parents reported becoming accustomed to carrying out the regimen, they nonetheless described it as something that made it difficult or impossible to live a normal family life. The father of a child with SCD noted: “It's difficult because you are trying to do normal things, but we have a lot of disappointments. We want to go somewhere and can't because he's not feeling well.” Other parents described the considerable effort required to engage in social activities and outings as evidence of the difficult nature of their lives. These parents did not believe that it ever would be possible to have condition management be less time-consuming or less of a focus of family life.

Parents' perceptions that the treatment regimen interfered with other activities contributed to their belief that their family life was different from and less satisfying than that of other families. For example, the mother of a daughter with PKU contrasted her life to that of other family members, saying, “It's horribly difficult. We have to make full-fledged meals every night. There are always more dishes involved. My sister's kids can have cereal for dinner in a pinch, but not here.” These parents' experiences with caring for a child with a chronic condition had convinced them that normalization, although desirable, was never going to be possible for their family. The absence of normalization was an enduring reminder to these parents of how difficult their life was in comparison to other families.

Parental Role

Parenting competence (NP group)—For parents in this group, normalization and their ability to balance condition management and other aspects of family life was viewed as evidence of their success as parents. They expressed pride in their ability to carry out the

treatment regimen and to act as advocates for their children in the health care and school systems. In addition to managing the treatment regimen, parents discussed their management of other aspects of family life related to the condition, such as employment decisions and discipline that signified to them that they were good parents.

Confidence in their ability to manage the condition and objective clinical evidence that their child was doing well contributed to the perception of being a good parent. One mother of a boy with hemophilia said, “We assess, we diagnose. He’s only been twice in his life to a doctor because of hemophilia.” This mother also took pride in her ability to assume full responsibility for condition management, saying, “The responsibility for it [management] was totally ours and we called the shots.” To this mother, her ability to take the lead in condition management signified that she was a good parent. Similarly, another mother, of a girl with CF, said, “I’m not afraid to say ‘no’ to something” when discussing the recommendations made by her child’s health care team, a comment that reflected her confidence in her ability to manage the condition and act as an advocate for her child.

Parents in the NP group did not dismiss or minimize the effort required to manage their children’s conditions. However, they perceived the effort as part of fulfilling the normal parental role. For example, the father of a boy with hemophilia stated, “You gotta do what you gotta do. I’m going to do whatever I have to make sure things are smooth for him.” In a similar vein, a single mother of a girl with SCD, despite describing worries about insurance coverage and acknowledging stress in times of SCD crises, said, “I have to do what I have to do as a parent to make sure my child is taken care of. I know she’ll be OK. I know I’m a good parent and I take care of her.” Parents in the NP group viewed condition management as one aspect of their parental role, not as a burden or a challenge to fulfilling their role. They spoke about knowledge of the condition and its management in the context of their overall parental responsibilities and their sense of competence in fulfilling the role.

A perception of a successful balance of work and family life also was indicative of successful parenting for these families. Some mothers spoke explicitly about their decisions to quit their jobs and stay at home as a decision made with the intent of improving condition management and family life. One mother of two children with PKU reported,

I know that they love the fact that I’m staying home full-time, and I know that they respect the fact that I used to have a profession, and the fact that I’ve given that up to stay home with them means that being their mother is an important thing.

In contrast, another mother spoke about her decision to continue working as a strategy to achieve a normal life in the context of her daughter’s CF, saying “I didn’t quit my job after she was born because I thought we’d need to have some stability, and keep things the same, and we did.” In these examples and in other interviews, parents described decisions about work as evidence of their competence as parents. Regardless of the decision, the parent’s goal was to fulfill their parenting role and create a normal life for their child and family. Perceptions that they had achieved these goals signified to them their success in managing the condition and parenting their children.

Although parents in the NP group sometimes referred to feelings of guilt and inadequacy, these feelings were described as being in the past or as fleeting and were seen as a normal experience for all parents. Feelings of guilt and inadequacy never were described as pervasive or threatening their overall sense of being a good parent. A father of a girl with PKU explained, “I think I got to where it wasn’t as much like I could blame myself. There’s no control over it.” Parents in the NP group acknowledged that occasional misgivings and feelings of guilt were things that all parents experienced as a normal part of being a parent but were not a threat to their sense of competence. They also acknowledged challenges to

parenting a child with a chronic condition, but saw them as ameliorating with time, signifying they had become more expert and confident in their parenting role.

Parenting self-doubt (NA group)—The absence of normalization was reflected in these parents' descriptions of how they fulfilled their parenting role. They provided numerous examples of parenting that signified to them the atypical nature of their parenting and their diminished sense of competence in the role. Parents in the NA group spoke about the same issues as parents in the NP group. However, their statements were focused on their ongoing sense of inadequacy, uncertainty, and guilt and how these compromised their ability to be good parents. Although these parents believed focusing family life on condition management was unavoidable, they also believed this focus compromised the quality of their parenting.

In the NA group, parents' comments implied that they would be better parents if their child did not have a genetic condition and described parenting as fraught with uncertainty and difficulty. The mother of a boy with Marfan's syndrome noted, "There's always something new. You feel like you're not accomplishing your goals. You're falling behind, and it's just agony and suspense." Another mother, of a boy with NF, described how the condition was linked to feelings of inadequacy as a parent. She stated, "NF definitely affected the way I parent unfortunately. There's a lot more stress." A single mother of a boy with SCD expressed pride in her knowledge of SCD, but went on to describe how difficult it was for her to translate that knowledge into effective condition management, stating, "I feel just helpless. That's how I feel. Sick cell is a situation that, like with my child, from minute to minute things could change." This mother's uncertainty about how best to manage her child's frequently changing symptoms impeded her sense of being a competent, confident parent and contributed to her belief that parenting a child with a chronic condition was especially challenging.

Parents, especially mothers, in the NA group uniformly expressed ongoing guilt about their child's condition or stated that they would have chosen not to have children had they known the child would have a chronic condition. For example, the mother of a boy with CF stated, "You just feel like it is your fault a lot of times." Other parents expressed similar feelings, including regrets about their decision to have a child. A mother whose first child did not have CF noted, "I shouldn't have had another child. I should have stopped when I had my first one." Parents also expressed guilt about instances when they believed their shortcomings as a parent had compromised their child's health or quality of life. A mother of a boy with NF discussed guilt related to treatment choices she and her husband had made in the past, stating, "I don't think we were his best advocate when he was little. I have guilt on myself and blame for my husband." These parents described ongoing feelings of guilt and regret related to fulfilling their parenting role in a way that assured the child's health and well-being. Based on their assessment of their inadequacies, some parents questioned the wisdom of the decision to have (more) children.

For parents in the NA group, satisfaction with the parental role remained elusive. Evidence for this comes from their consistent focus on perceptions of inadequacy as parents and their feelings of guilt. This focus on persistent inadequacy highlights key differences between the NP and NA groups with regard to the temporality of perceptions and the meaning of objective indicators of their child's health. Parents in the NP group acknowledged the existence of guilt and occasional perceptions of inadequacy in the parental role, and that normalization was not a static state, but they did not see these as a serious threat to the essential normalcy of their family life or their ability to be good parents. In contrast, parents in the NA group emphasized that the challenges they faced as parents were unchanging and extraordinary, precluded having a normal family life, and compromised the quality of their

parenting. Moreover, perceptions of ongoing parental inadequacy were not linked to their reports of objective evidence of their child's health or the complexity of the management regimen. In contrast to parents in the NP group, who described their child's health status as evidence of their condition management and parenting competencies, those in the NA group described a sense of inadequacy and uncertainty even when they reported clinical indicators suggesting their child was in excellent health. For parents in the NA group, such objective evidence that their child was doing well was not interpreted as evidence of being a good parent.

Impact on Family Life

Recognition of positive outcomes (NP group)—Parents in the NP group identified positive aspects of having a child with a chronic condition. Thus, normalization not only signified that they were managing well, it also signified that they were managing in a way that contributed to the overall quality of their family life. In some cases, newfound competencies and unexpected benefits were linked directly to the requirements of the treatment regimen. For example, the mother of a child with thalassemia stated:

The first 6 months were hard, but I knew I had to be in good shape mentally and physically to take care of my children. The more I came to the reality that it's not a big deal, the more strength and courage I was getting. Our families have been great. If anything, we are a much closer family because of this.

Parents also described positive job changes and career decisions they made as a result of having a child with a chronic condition. A father of a child with PKU described the positive impact of the condition on his life, stating, “When our daughter was born it caused me to reorder my priorities. I put taking care of her and being a more involved dad much more at the forefront. I switched to a less demanding job.” Parents believed that some of the changes they had made in their lives to balance condition management and other aspects of family life had contributed to a more fulfilling family life. These parents acknowledged that family life had changed in some ways because of the condition, but they also described a sense of continuity with the past, positive aspects of changes they had experienced, and optimism about the future.

Maintaining a balance between adhering to the treatment regimen and other aspects of family life was described as the outcome of deliberate effort rather than the natural evolution of life with a child with a chronic condition. Parents indicated that after an initial period of adjustment, their goal was to balance taking care of the condition with other aspects of their lives and they engaged in purposeful efforts to achieve this goal. Normalization signified to these parents that their efforts had been successful. The mother of a daughter with PKU said:

We are determined that things are going to fit in, and that we are going to adapt. It's not going to be a problem. I think we just have that philosophy. We can either make it a problem or decide how we are going to incorporate it into our lives and go on.

Parents believed that normalization reflected the achievement of a valued goal of taking care of the condition while minimizing its impact on family life. Parents in the NP group acknowledged the sad and challenging aspects of having a child with a chronic condition, but they also recognized positive aspects of the experience. Moreover, these positive aspects signified to them their success as parents in creating and sustaining a normal family life.

Focus on negative outcomes (NA group)—In sharp contrast to parents in the NP group, those in the NA group associated difficult management with negative outcomes for both their family and individual family members. These parents believed having a child with

a chronic condition contributed to a more difficult, less satisfying family life and compromised their effectiveness as parents. Moreover, in contrast to parents in the NP group, these parents anticipated that life was likely to become more difficult in the future. Thinking ahead to when her daughter would begin school, the mother of a child with CF stated:

This is one of the hardest things ever, and it's not going to go away. I feel isolated because I don't think people understand. It's hard. I can't keep a steady job. People ask what they can do to help, but there isn't much they can do. We have to do everything ourselves.

In addition, parents in the NA group viewed the condition as negatively affecting their opportunities for personal growth and fulfilling life experiences. For example, the single mother of a child with SCD reflected on her limited social life, stating:

When I go out with anyone I want him to know my family situation. So far it's been very limited, to tell you the truth. The men I have met feel it would be a pretty stressful thing that they couldn't handle.

In sum, for these parents, the absence of normalization signified the negative consequences of having to focus family life on condition management.

Parents in both the NP and NA groups acknowledged that the child's condition had an impact on family life, and linked normalization to that impact. However, those in the NP group were able to identify positive personal and family outcomes they attributed to normalization; parents in the NA group emphasized the negative consequences of condition management for their personal and family life.

Discussion

In her article on families' efforts to construct a normal life in the context of a member's chronic condition, Robinson (1993) concluded that "normalization is a carefully constructed story that gives meaning and guides behavior" (p. 26). The current analysis contributes to a more specific delineation of the meanings parents attribute to a family life that is characterized by the presence or absence of normalization. In undertaking this analysis, it was anticipated that the process, meaning, and outcome aspects of normalization would be differentiated more precisely. However, we found how closely these three are intertwined. Parents' descriptions of management strategies were interwoven with their comments on what these strategies signified (e.g., evidence of competent parenting, successful adaptation). Two distinct patterns of meaning were identified that parents attributed to their ability or inability to normalize family life.

For parents in the NP group, normalization was seen as a notable accomplishment and evidence of successful adaptation. They identified normalization as a family strength, one that contributed to the overall functioning of the family and individual family members. For these parents, normalization signified that their family was doing a good job of adapting to the child's chronic condition. The theme of doing a good job was reflected in parents' statements about how the family incorporated condition management into ongoing family life and their descriptions of themselves as parents. These parents also linked normalization to positive individual and family outcomes. Normalization was a source of pride in the present and motivation for the future.

On the other hand, for parents in the NA group, the absence of normalization signified that their lives were different from and more difficult than those of other families. Because of the effort required to carry out the treatment regimen and other challenges associated with the

child's condition, these parents believed they had no choice but to focus family life on condition management. As a result, family life was viewed as more difficult than that of other families. Moreover, they described how the added work and disruptive nature of managing the condition made family life and the lives of individual family members less satisfying. For these parents, the absence of normalization also signified their inadequacies as parents. They did not identify positive outcomes resulting from having a child with a chronic condition.

Past research on normalization has identified how families come to define life in the context of childhood chronic illness as normal and the behavioral strategies they use for managing the condition without making it the focus of family life. This emphasis is reflected in the most recent concept analysis by Deatrick et al. (1999), who identified the defining attributes of normalization, but also pointed to the need for more research on its antecedents and consequences. Robinson (1993) revealed the process by which families initiate and enact a story of "life as normal." Although less emphasized in her work, she also described hope as an outcome of normalization that "enables persons and families to carry forward through adversity" (p. 23). The current analysis points to the interplay of strategies parents use to manage childhood chronic conditions, the meanings they attribute to those efforts, and their overall assessment of the consequences of the presence or absence of normalization for family life.

For the most part, the literature on normalization is predicated on the assumption that it is a positive family response to having a child with a chronic condition (Deatrick et al., 1999; Dochterman, & Bulechek, 2004; McDougal, 2002). The meanings parents attributed to normalization in our study further specify the positive elements of this response and clarify the ways in which it is a family strength. Normalization may be an important mediator of illness-related stressors (e.g., treatment demands, uncertainty) on family outcomes, and this is a promising direction for future research. In addition, parents' reflections on the link between normalization and parental competence points to the importance of looking at the relationship between normalization and child outcomes, something not possible in this secondary analysis, because data on child functioning were not collected in the larger study.

Also of interest is the reference group parents use to assess the quality of their management efforts. In the current analysis, parents spontaneously compared their family life to that of families without children with chronic conditions. For parents in the NP group, the comparison was positive and provided evidence of successful condition management and parenting. In contrast, for parents in the NA group, comparing themselves to families without an ill child served to highlight the unusually difficult aspects of their family life and contributed to their sense of inadequacy as parents. As such, parents in the NA group stood in sharp contrast to those in Rehm and Bradley's (2005) studies of families with a technology-dependent, medically fragile, and developmentally delayed child. They found that these families viewed their family circumstances as very different from those of most families and relinquished the goal of normalization. These parents focused their efforts on creating a good life for their family despite their unique situation. Unlike the parents in the NA group who attributed negative outcomes to their inability to normalize, parents in Rehm and Bradley's sample saw their ability to create a good, though not normal, life.

The current results were different also from those of Morse et al. (2000), who studied mothers of children who were technology-dependent. Parents in the Morse et al. study talked about moving between the world of the normal and the world of the disabled; whereas parents in the current sample spontaneously compared their family life to that of families without children with chronic conditions. It is likely that the differences in the current findings and those from previous research are a function of very different samples in terms

of the severity of the child's impairment. None of the children in this study were technology-dependent or developmentally delayed and, although some had life-shortening conditions, most parents viewed their child's health as good at the time of the interview. More research is needed on the relationship between the identified reference group and parents' normalization efforts. Although Robinson (1993) found that parents deliberately adopted a normalcy lens for guiding their response to their child's condition, little is known about the consequences of relinquishing a normalcy lens for child and family functioning, and this is another promising area for future research.

Although acknowledging how closely linked the process, meaning, and outcome dimensions of normalization are, it also is important for investigators to clarify their particular area of interest and tailor data collection strategies to elicit appropriate information. For example, studies of the links between management strategies and the consequences for family life would be strengthened by the addition of interview questions and probes that go beyond management behaviors to include parents' perceptions of the consequences of their management strategies for family life. Currently, there is no structured measure of normalization, and the recognition of process, meaning, and outcome as distinct aspects of this concept as well as the insights this analysis provides on the meanings parents attribute to normalization should inform future instrumentation studies.

Although it is difficult to know why some families achieve normalization and others do not, there was evidence from this analysis that parents' ability to adapt the treatment regimen to the family's usual routine and to redefine normalcy as inclusive of condition management were pivotal components of normalization. Future researchers should focus on developing and testing interventions to help parents master the treatment regimen and fit it into their everyday life. Another likely direction for future studies would be to examine how normalization changes and may need to be supported differently over time as the child matures and the family's situation changes.

Clinical Implications

Useful insights were provided into how health care providers can support families' normalization efforts and the importance of doing so. Recognizing the importance and positive outcomes that parents attributed to successful normalization efforts, health care providers can work with them to incorporate effective condition management into ongoing family life, including adapting treatment regimens to the family's particular circumstances. The Nursing Intervention Classification System (Dochterman & Bulechek, 2004) includes normalization promotion as an intervention and lists a number of specific strategies to help families reach this goal, including "provide opportunities for child to have normal childhood experiences" and "assist family in altering prescribed therapeutic regimen to fit normal schedule when appropriate" (p. 517). To set the stage for discussing strategies to support normalization, it also would be important to assess parents' perceptions of what normalization would entail for their family and the extent to which it is viewed as a desirable, achievable goal. Providers also could use their assessment of the family's situation and goals to determine whether the proposed treatment regimen may need to be modified to support family goals. Health care providers can play an important role helping parents determine when condition management is the appropriate focus of family life and reassure them that a temporary need to focus on condition management is normal and does not signify that normalization will never be possible again.

Providers can play an especially pivotal role in working with parents who believe that adherence to the treatment regimen means that family life and parenting, of necessity, revolve around condition management. Although some parents in our study identified negative consequences of their singular focus on condition management, they perceived this

as their only alternative. Parents in the NA group discussed failed normalization efforts related to such things as last-minute cancellations of family outings and time-consuming treatment regimens that left little time for other activities. These parents' intermittent, unsuccessful normalization efforts had convinced them that normalization was impossible for their family, and they would have benefited from guidance and support from health care professionals. Parents in the NA group rarely spoke of efforts to adapt the treatment regimen to the family routine, nor did they recognize that normalization of family life will invariably wax and wane over the course of the child's illness. Having not achieved normalization, they gave up. For parents such as these, health care providers could acknowledge the difficulty of their situation and work with the family to identify strategies and resources that would make condition management less difficult. In particular, parents such as those in the NA group may benefit from being put in contact with parents who have been able to create a normalized family life. Other parents are in an especially good position to acknowledge the effort that goes into normalization as well as the benefits. They also can share tricks of the trade for managing the condition and provide encouragement and perspective when setbacks occur (Gallo & KnafI, 1998).

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