Developmental Disabilities Bulletin, 2004, Vol. 32, No. 1, pp. 84-110

The experience of transformation in parents of children with disabilities: Theoretical considerations

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Many parents assert that, despite the considerable and sustained stresses involved in parenting a child with a disability, their experiences have been personally transformative. Increasingly, researchers are advocating for a theoretical understanding of family life management following the diagnosis of disability in a child, with an emphasis on family strengths and resilience, attestations of positive or beneficial effects of parenting, and a wider range of possible parent and family outcomes, including transformation. The purpose of this paper, therefore, is to explore the experience of transformation in parents of children with disabilities, based on concurrence between data from ongoing research with parents and broader theoretical assumptions on the nature and experience of life transformation, and to propose a model that identifies several critical processes that may facilitate transformation. Data from interviews with three parents of children with a range of disability characteristics are presented to support both the explanatory value of the model and its utility to practitioners.

Recent research has indicated that, despite the increased demands of parenting a child with a disability, many families are able to manage life effectively. For example, in a large-scale study comparing stress and coping measures in mothers of children with intellectual disability with mothers of typically developing children, Emerson (2003) cautioned against associating raising a child with intellectual disability and increased maternal psychological distress and negative family outcome. While many of the mothers of children with intellectual disability reported additional stress in their lives, only a minority of them experienced adverse psychological, social or familial outcomes. In fact, Emerson stated, "Mothers were just as likely to report that their child's difficulties had strengthened their relationship with their partner as they were to report that it had weakened their relationship" (p. 397). Similar studies conducted with Australian, Korean, Canadian, European, and American parents of children with a range of disability characteristics report such positive personal and family outcomes as the formation of stronger family ties, increased sensitivity to socially disenfranchised people, and the development of a more authentic perspective of what is important in life (Behr, Murphy, & Summers, 1992; Bower & Hayes, 1998; Cho, Singer, & Brenner, 2000; Scorgie & Sobsey, 2000; Scorgie, Wilgosh, & McDonald, 1999; Scorgie, Wilgosh, Sobsey, & MacDonald, 2001; Stainton & Besser, 1998; Taunt & Hastings, 2002; Wilgosh, Nota, Scorgie, & Soresi, 2004). Increasingly, parents are asserting that, despite the considerable and on-going stresses involved in parenting a child with a disability, their experiences have been personally transformative (Gill, 1997; Green, 2002; Steele, 2000). For instance, Green (2002), the mother of a child with cerebral palsy, recently began an article with the words, “Raising a child with a disability is a profoundly transformative experience” (p. 21). She explained how parenting her daughter, Amanda, “opened up some areas of my soul that would otherwise lie dormant” (p. 24) and led to profound personal and life perspective changes. Similarly, Steele (2000), the father of a daughter with progressive physical disability, described the transformation he experienced as “a kind of conversion,” a “self-transcendence” that encompassed, among other outcomes, a heightened sense of compassion toward life (p. 165).

Early research describing parent adjustment following the diagnosis of disability in a child contended that parents progress through linear stages of coping, such as grief-adaptation, which often focused on stress reduction as a primary outcome (Aldwin, 1994). However, Roll-Pettersson (2001) interviewed 46 parents of children with moderate to severe cognitive disability and found that, for the majority of parents, there was “. . . insufficient evidence to support professionals continuing to adhere to the adaptation-mourning model [of adjustment], together with its associated pathological-dysfunctional paradigm” (p. 1). Increasingly, researchers are advocating for a revised theoretical understanding of family life management following the diagnosis of disability in a child, with an emphasis on family strengths and resilience, attestations of positive or beneficial effects of parenting, and a wider range of possible parent and family outcomes, including transformation (cf. Grant, Ramcharan, & Goward, 2003; Taunt & Hastings, 2002).

The purpose of this paper, therefore, is to explore the experience of transformation in parents of children with disabilities and to propose a theoretical model that identifies several key processes that may facilitate transformation. Our goal is not to present a definitive view of transformation. It is, indeed, quite unlikely that such a task could be accomplished. Rather, our goal is to propose one possible way of understanding parent transformation based on concurrence between data from our ongoing research with parents of children with disabilities and broader theoretical assumptions on the nature and experience of life transformation. Data from interviews with three parents of children with disabilities representing differing ethnic backgrounds will be used to provide evidence of the explanatory utility of the model.

A Theoretical Examination of Transformation

Interest in how people manage stress has been growing steadily during the past several decades. What is even more intriguing to some researchers is the assertion by some individuals that the experience of a traumatically stressful event in their lives has led to positive life changes (Barnard, 1994; Janoff-Bulman, 1992). These people claim to have actually benefited from, or been "blessed" through, their experience with a profoundly difficult life incident. Such transformational statements have undermined two implicit assumptions about stress and coping: that stress is by nature negative in consequence, and that the primary goal of coping is to return to a former state of equilibrium (Aldwin, 1994; Newman, 1995). There are times when a life event is so profound that adaptation requires a major change. For this reason, Aldwin (1994) asserts, "Rather than simply a homeostatic function, the more important role of coping may be transformation" (p. 270). This attestation leads to two questions regarding the experience of transformation: is transformation linked to positive outcomes and, if so, what is the process by which transformation occurs?

Transformational Outcomes

Recent research in the fields of psychology and nursing has indicated that optimal personal and family outcomes are associated with the experience of transformation (Carpenter, Brockopp, & Andrykowski, 1999; Coulehan, Friedlander, & Heatherington, 1998; Courtenay, Merriam, & Reeves, 1998; Courtenay, Merriam, & Reeves, 2000; Paterson, Thorne, Crawford, & Tarko, 1999). For example, Paterson et al. (1999) conducted a qualitative study of transformational outcomes in persons living with Type I diabetes. They found that positive transformation, such as an enhanced sense of self, meaning, and personal mastery, was related to patients' positive outcomes. Similarly, Courtenay et al. (2000), in a follow-up study of fourteen persons with HIV, found that transformation documented in their first study, such as making meaningful life contributions, a heightened sensitivity to life, and a desire to be of service to others, held stable across a two-year time frame. This finding, they claimed, confirmed the notion that transformation, once experienced, was irreversible (cf. Newman, 1994). Moreover, not only did the initial transformation hold up, but in the follow-up study the participants articulated additional transformation in "meaning schemes," such as a more future-focused life perspective, greater valuation of self-care, and formation of a new self-identity incorporating HIV.

In a comparative study of women with breast cancer and a control group, Carpenter et al. (1999) found that women with breast cancer who had experienced positive transformation scored higher on measures of self-esteem and personal well-being than either a control group or women with breast cancer who had not experienced transformation. Variables associated with positive transformation included having the courage, the inner strength, the external supports, and the expectations required to deal with a potentially life-threatening diagnosis and to make necessary life and self changes.

Research in the field of parenting children with disabilities also points to the occurrence of parent transformation. For example, Scorgie, Wilgosh, and McDonald (1996) conducted interviews with fifteen parents of children representing a range of disability conditions (e.g., deafness, autism, Down syndrome, severe developmental delay, and rare metabolic conditions) who resided in Western Canada. Using questions such as "How has raising your child changed you?" and "What has your child taught you that you might not have otherwise learned?" they organized transformational statements into three themes: personal transformation (e.g., changes in self-identity), relational transformation (e.g., changes in the way one relates to others), and prespectival transformation (e.g., changes in one's assumptions about life and what is important).

In order to test their findings across a wider population of parents, Scorgie et al. (1999) developed a survey instrument, the Life Management Survey, which was given to two groups of parents in Western Canada, one representing parents judged by agency personnel as effective at managing their personal and family lives (n = 80) (Scorgie et al., 1999), and a second non-specified group of parents (n = 116) (Wilgosh, Scorgie, & Fleming, 2000). Parents were asked to rate, on a 5-point Likert scale, the extent to which they agreed or disagreed with a number of statements describing personal changes or transformations (e.g., "I have a different and more authentic view of what it means to be successful in life," "I have learned to see life from a different perspective," and "I am more compassionate toward others"). The results of these two survey studies corroborated the earlier qualitative findings with regard to the experience of transformation. Furthermore, since the broader study sample contained sufficient numbers to warrant subgroup examination (severe disabilities [Wilgosh & Scorgie, 2000], Down syndrome [Scorgie, et al., 2001], and autism [Scorgie, Wilgosh, & Sobsey, 2004]), the researchers were able to ascertain strong similarities among the three sub-groups on the experience of transformational outcomes.

More recently, the Life Management Survey has been administered to two groups of Italian parents, the first (n = 107) consisted of parents of children with Down syndrome, gonadotrophin-releasing hormone disorders and Turner syndrome (Wilgosh et al., 2004), and the second (n = 204) consisted of parents of children with visual impairment, hearing impairment, autism, Down syndrome, and no disability (Nota, Soresi, Ferrarai, Wilgosh, & Scorgie, 2003). Results from the two Italian studies corroborated the Canadian studies, indicating substantial consistency cross-nationally as well as across disability characteristics. Furthermore, in the second study, the researchers found that the experience of transformation either directly or indirectly influenced quality of life in parents of children with visual impairment, hearing impairment and Down syndrome.

Since transformation seems to be associated with positive outcome, it is important to understand both the processes that lead to transformation and ways in which these positive outcomes might be facilitated.

The Process of Transformation

In her Theory of Health as Expanding Consciousness, Newman (1994, as cited by Wade, 1998) purports that a difficult life event may bring a person to an awareness that "old ways of thinking and acting"--the old rules--no longer work (p. 716). When this occurs, the individual experiences disequilibrium and uncertainty. Rather than viewing this disorganization negatively, Newman asserts that disequilibrium may serve a constructive role by bringing the individual to a "critical choice point," or a turning point, that causes the person to actively seek a new set of rules—a new way of seeing the self and the world—that propels him/her to a new level of self-definition. This process of "expanding consciousness" enables a person to experience such transformations as enhanced self-awareness, "greater meaning in life and new dimensions of connectedness with other people and the world" (Newman, n.d., para. 1). Newman asserts that movement through the stages of disorganization and uncertainty to higher order transformation can be facilitated by a supportive partnership with a caring and supportive person, such as a nurse.

As a result of a study of transformation experienced by breast cancer patients, Taylor (2000) proposed a four-phase model of transformation. During phase one, "encountering darkness," newly diagnosed patients dealt with the question, "Why me?" as they sought to come to terms with their diagnoses. Phase two, "converting darkness," entailed patients making decisions about how they would deal with their cancer and what courses of action they would pursue. In phase three, "encountering light," patients acknowledged that their experience had produced positive outcomes, such as re-prioritized personal values, enhanced purpose and enjoyment of life, increased self-knowledge and growth in personal spirituality. The final stage, "reflecting light," was characterized by life-change statements such as patients affirming they had become better persons or gained wisdom through the experience of breast cancer. Taylor identified a number of variables that initiated and facilitated transformation in women with breast cancer, such as whether the woman perceived cancer to be life-threatening, and the extent to which she experienced a loss of personal control and was "worried" about the well-being of family members. She also listed variables that were related to the intensity of the transformational process, such as the person's ability to confront and deal with negative emotions, amount of suffering endured, strength of personal spirituality, age, and history of personal coping and transformation.

Coulehan et al. (1998, cited in Etchison, 2000) depicted a three-stage model of transformation from their research involving eight families who were undergoing group counselling for a chronic family problem. During the first stage, family members explored alternate ways of perceiving, explaining, and understanding their problem and its cause. In the second stage, researchers documented a shift, or transformation, in family members' attitudes and feelings towards themselves and others, from negative to more accepting. Finally, in stage three, family members were able to focus on and articulate the positive attributes of the family and each individual member. These findings lend further support to the role of professionals in facilitating the formation of positive transformation in families.

Mezirow (1997) maintains that transformation can also occur in learning environments, when learners are engaged in critical reflection designed to examine the sources and content of the foundational assumptions that underlie their beliefs about the world and how those beliefs shape and delimit thought and behavior. Transformational learning is often initiated through the presentation of a "disorienting dilemma" or crisis which causes learners to re-evaluate the efficaciousness of their assumptions using either personal reflection or reflective discourse with others (Baumgartner, 2001). Transformation of perspective occurs when assumptions are retooled to incorporate new interpretations of the self, others, or the world (Mezirow, 1997). Giroux (1992, as cited in Baumgartner, 2001) purports that the ultimate goal of learning is transformation, for learning should not only change how people think, but ultimately shape who they are.

In a review of research on transformation, Wade (1998) concluded that researchers agree on a number of universal components of a transformational experience. First, transformation is usually precipitated by an antecedent, or disorienting dilemma, either occurring naturally or contrived, which disrupts the stability of one's life and belief system. Secondly, to enter the process of transformation the person must at some point choose consciously and willfully to face the dilemma and work through it. Thirdly, during the process of transformation a number of "critical elements" are at work which involve the release of old assumptions and self definitions that no longer work, and the active construction and integration of a new self-identity and assumptive views (p. 716). Finally, the outcome of transformation involves the realization of personal growth and empowerment as well as the acknowledgement of loss. Furthermore, Wade (1998) purports that, while transformational insights can be ongoing throughout life, "once transformation has occurred, the individual never returns to the old perspective" (p. 716-717).

While the experience of transformation is not domain specific, Wade (1998) calls for "qualitative research to identify patterns associated with transformation," with the goal of providing a concept of transformation that has operational utility. We propose the following model as an attempt to address this need.

Parent Transformation: A Working Model

The model we propose of parent transformation (see Figure 1) illustrates three processes that we believe may account for transformation in parents of children with disabilities. Diagnosis of disability represents, for most parents, a disorienting dilemma which disrupts life and challenges beliefs. The purpose of the model is to suggest "critical elements" of the process that parents experience as they release old assumptions and self definitions that no longer work and actively construct a new self-identity and assumptive views following diagnosis.

We offer this conception of transformation, however, with one caveat. Though each of the three processes serves a different and important function and, thus, warrants specific investigation, it is doubtful whether they represent three discrete phenomena. Rather, the three processes overlap. It might be argued that transformation involves a single all-encompassing process. Nonetheless, examination of various aspects or nuances of the process may have implications for how professionals collaborate with parents. Thus, our model depicts transformation as three connected and overlapping processes that are used to resolve the dilemma experienced by parents resulting from diagnosis of disability in a child.

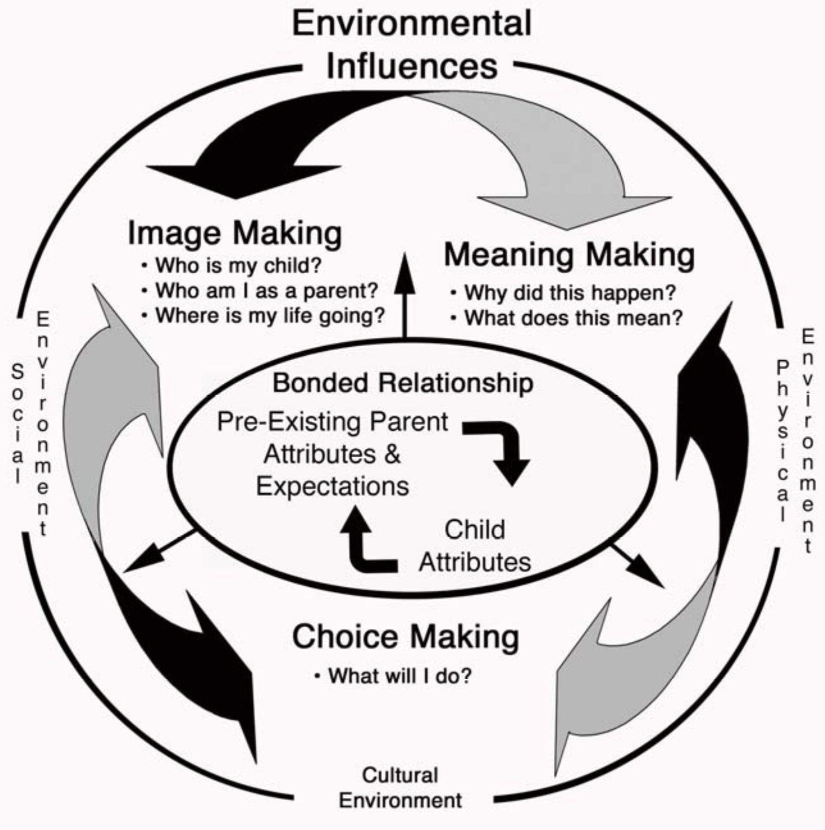

Figure 1. Processes used to answer emerging questions. Transformations occur when radically different answers are constructed to reconcile the child parent relationship with expections formulated by parent's previous relationship to the environment.

Bonded Relationships

Research on parent-infant attachment intimates that attachment begins, not at birth but long before, when a mother (or couple) first realizes that a child has been conceived. Robinson, Baker, and Nackerud (1999) purport that:

> maternal attachment consists of a complex set of events that include not only tangible events, such as fetal movement, but also events such aspreparation and adjustment to the pregnancy that begin the relationship. Prior to birth, the mother has been able to conceptualize the infant and to project the way the presence of the infant will contribute to the life of the family. (p. 261)

In other words, pregnancy marks a new beginning, and a future orientation. Long before birth, parents are forming images of themselves, their baby, and the future life they will share together according to personal and socially conscribed values and beliefs. Prenatal bonding also includes feelings of commitment and affection by the parents toward the child and the life they will share together (Siddiqui, Hagglof, & Eisemann, 1999). Following birth, parents continue to attach to the infant that they, in some ways, already know and love. And they begin to live out the life they formerly imagined sharing together.

Critical Emergent Questions

Diagnosis of disability in a child is, for most parents, a traumatic experience (Dyson, 1993; Green, 2002; Kearney & Griffin, 2001). Often parents are bewildered, feeling as if they have been plunged into an unknown world with little warning. In the early stages following diagnosis, parents are confronted with a number of critical emergent questions as they strive to cope with the diagnosis and move forward. We have organized these critical questions under three general categories: life trajectory identity-oriented questions, existential meaning-oriented questions, and personal and family choice-oriented questions. Each of these question categories, in turn, sets in motion a process that, under certain conditions, may lead the parent to experience transformation. For the sake of clarity, we will set forth and discuss our model in two segments: critical emergent questions and transformational processes.

Life trajectory identity-oriented questions. Bowman (1999) purports that traumatic life events often incorporate “loss of dreams.” He defines this as “the loss of an emotionally important image of oneself, one’s family, or one’s situation; the loss of what might have been; abandonment of plans for a particular future” (p. 181). Parents’ accounts of diagnosis of disability in a child widely support this concept of loss (cf. Green, 2002; Kearney & Griffin, 2001; Steele, 2000). For example, Green (2002) infers that parents experience a “double loss”—the loss of the child they imagined would be, as well as the loss of a culturally defined future life in which they, too, play a role. She asserts that parents are often thrust into “a stigmatized social category for which their previous experiences have generally left them ill prepared” (p. 21). Similarly, Steele (2000) describes grief following diagnosis as akin to suffering a death, not of the child but of “all the cherished expectations for her life” (p. 168). Furthermore, Steele contends, following diagnosis a parent’s sense of pain is compounded by his/her ability to envision the life-long consequences of the diagnosis on the child. When disability is severe and irreversible and the child’s dependency needs are high, parents are required to envision lifestyle changes that may impact on them throughout their lives.

Without doubt, diagnosis of disability involves implications for the entire family (Muscott, 2002). It can shatter a family’s understanding of who they are and what their lives will be like, both at present and in the future. Therefore, following diagnosis the first category of emergent questions focuses on identity. Parents look at their child and ask: “Who is my child?” “Who can he/she become?” They look at themselves and ask: “Who am I as my child’s parent?” “Who can I become?” And they look at their lives and ask: “What is my life going to be like, now and in the future?”

Existential meaning-oriented questions. Secondly, in the days following diagnosis many parents try to make sense of the diagnosis and its impact on their lives. Psychologists have long maintained that human beings are meaning-makers and, as such, seek to understand and ascribe meaning to life experiences (Meichenbaum & Fitzpatrick, 1993; Mezirow, 1997). Encounters with traumatic events often challenge normal schemes of meaning, forcing persons to search for new ways of understanding and interpreting life events. In a letter to her daughter born with Down syndrome, Janz describes her thoughts in the delivery room, “I wondered, where did you come from? How could I have produced you? Where did things go wrong? And why, why, why?" (Badry, McDonald, & LeBlond, 1993, p. 1). Similarly, in a poem that describes her feelings following diagnosis, Green (2002) writes, "Oh grief; horrid, unbearable, unending grief. I've lost my shining angel—precious child. How could life have so abandoned her at this early age?" (p. 24).

In addition to their own questioning, many parents encounter and have to respond to interpretations forced upon them from extended family members and others, such as the belief that the child's disability was sent as punishment for some earlier wrongdoing. Such guilt-inflicting comments require parents to search for answers that made sense out of what Green (2002) calls, "this catastrophe" (p. 168). Therefore, the second category of emergent questions centers on the meaning questions: "Why did this happen to us?" and "How can I make sense of it?"

Personal and family choice-oriented questions. Finally, as parents deal with the loss of the image of the child they imagined, the child is still very much present in their lives (Green, 2002). And while parents are still struggling to answer the "Why?" questions, they also find themselves wondering how they are going to manage life day-to-day, week in and week out. Therefore, the third category of emergent questions has to do with parents' life-management concerns: "How am I going respond?" and "What options are available to me and my family?"

Transformational Processes and Outcomes

Questions require answers. Sometimes answers are apparent. But when a question challenges one's basic assumptions about the self, and the world and how it works, crafting a solution can require intense effort. It might also demand major changes in one's self-perception and perspective on life (Newman, 1995). We purport that the critical emergent questions parents face following diagnosis set in motion three processes: image-making, meaning-making and choice-making.

Image-making: Responding to the identity question. We live our lives according to a socially conscribed set of schema that serve as a framework for understanding the various roles and responsibilities people generally assume across a lifespan (Janoff-Bulman, 1992). In other words, we live with the expectation that our lives will correspond to typically prescribed roles filled at various times across a socially prescribed life-trajectory. But when a child is diagnosed with a disability, parents realize that their lives may change considerably. Whether or not parents can adapt to these changes and re-image hopeful identities and life-trajectories for themselves and their children will determine their ability to experience positive outcomes (Green, 2002; Hartshorne, 2002; Taanila, Jarvelin, & Kokkonen, 1998).

Following diagnosis of disability, parents must construct new images of their children, themselves and their lives. For most parents, this task of re-imaging is concurrent with grieving lost child, parent and life-trajectory images (Bowman, 1999). Furthermore, many parents bring to the diagnosis of disability in their children powerful images of disability that have been formed through past experiences with persons with disabilities or through societal beliefs about disability (Scorgie & Sobsey, 2000). Additionally, events surrounding diagnosis can influence image-making, either negatively or positively.

Many parents actively search for information about their child's disability, both to help them form realistic child and self-images, and to give them some sense of what their future life-trajectory might look like. Taanila et al. (1998) concur that information parents receive at the time of diagnosis shapes subsequent images that parents create of their child and his/her future life. When information is "unduly pessimistic," family functioning may be affected. Some parents assert that they live in a state of tension created by their need to construct hopeful child and life-trajectory images in the midst of progressively debilitating child prognoses (Steele, 2000). The need to balance both joy and sorrow may cause them to limit thoughts of the future, focusing instead on life in the present (Kearney & Griffin, 2001).

Some parents ardently assert that they have changed in ways that they claimed they would not have experienced apart from parenting their children. For example, in a study by Scorgie et al. (1999), a mother of a child with Down syndrome remarked:

> I don't know what kind of a person I might have been if I hadn't had Nathan. I really don't spend much time thinking, "Well, what would life have been like if Nathan had been 'normal?'"

> But I do spend time thinking about, "What would I have been like without Nathan?" (p. 402-403)

Other parents spoke of becoming stronger and more compassionate, caring, patient, self-assured, confident, outgoing, spiritual, and self-defined (Scorgie et al., 1999). Some also experienced vocational and interpersonal life changes.

While these statements are sometimes dismissed as illusion, personal transformations should not be viewed as uncommon. When one is forced to develop a new image, it should not be surprising that, especially in persons who achieve adaptive outcomes, the new image is significantly superior to one previously held. Steele (2000) concurs, "It often takes tragedy to activate our human capacity for self-transcendence" (p. 165). When one has had to face significant challenges and has prevailed, certainly one sees oneself in a new light. One may even see him/herself as vastly different from the person he/she formerly was (cf. Bloomer, 2001). Image-making, therefore, is one process that can lead to eventual transformation. However, it is closely tied to a second process.

Meaning-making: Responding to the "Why?" question. A few weeks ago, one of our graduate students bounded into class with a beaming smile on her face and joyfully announced that she had just learned that she was pregnant. Her classmates congratulated her heartily and then someone asked her the customary question--whether she was expecting a boy or a girl. Without pause, she delivered the standard reply, "Oh, we don't care if it's a girl or a boy, as long as the baby's healthy." What this young woman was expressing was a socially negotiated view of health and disability, namely, that giving birth to a child with a disability is a great tragedy. Having a child diagnosed with a disability can shatter the illusion that, if we are basically good people and live life uprightly, bad things won't happen to us (Fries, 1997; Janoff-Bulman, 1992). Thus, following diagnosis many parents struggle to "make sense of" the disability and to construct some type of personal interpretation of what happened, why it happened, and its impact on the parent's belief system about the world and how it works (Meichenbaum & Fitzpatrick, 1993). That is, parents engage in meaning-making in response to the question, "Why?"

Frankl's (1984) seminal work on the importance of meaning-making in the midst of crisis served as the catalyst for the development of an innovative approach to psychotherapy, which he called *logotherapy*. Central to Frankl's theory is the principle of "tragic optimism," or the belief that people have within themselves the capacity to creatively turn suffering into "something positive or constructive" when they find meaning in it (p. 162). Steele (2000) ascribed much of his own transformation to his belief that one can endure suffering if one can ascribe meaning to it. He purports, "You must construe your misfortune as opportunities, convert your 'fate' into 'destiny,' and search out what might be called the 'surplus of meaning' implicit in every calamity" (p. 172). Steele describes the new meanings that emerged from parenting his child as "liberating truths" (p. 173).

Janoff-Bulman (1992) describes meaning-making as "a creative process, though a particularly difficult and painful one" (p. 114). She believes that "the ability to transform the experience, to reinterpret the powerful data" is essential to resolving a crisis (p. 114). In fact, psychologists claim that continual, unresolved rumination may indicate that meanings have not yet emerged or that the meanings constructed thus far are insufficient to support positive functioning (Meichenbaum & Fitzpatrick, 1993). But how does one go about re-interpreting powerful data and forming new meanings?

In their research on transformations experienced by persons with HIV, Courtenay et al. (1998) described the importance of a "catalytic event," or some experience that enabled the person to get "unstuck" from inadequate patterns of thinking so that he/she could begin to form more constructive ways of thinking about and reacting to the disease (p. 78). However, catalytic experiences are not the only way parents construct new meaning, nor should they be held as essential. Some parents search for meaning in religious beliefs or in their own personal philosophies (cf. Tarakeshwar & Pargament, 2001). Some find great strength in the belief that "life has a purpose," even if one must wait many years for that purpose to emerge (Scorgie & Sobsey, 2000). Conversely, other parents contend that sometimes random things happen and searching for a purpose is futile (Green, 2002). Still, others express the belief that no one is exempted from experiencing difficulties (Scorgie & Sobsey, 2000). The key for them is to believe that good can emerge, not so much from, but in the midst of the difficulties of life.

Like image-making, it is not surprising that parents who learn to manage life effectively form new meanings and perspectives on life, meanings that may even be transformative (Kearney & Griffin, 2001). When a child is not going to grow up and reach a parent's "dreams" or conform to society's template, a parent is forced to reconstruct his/her definition of a meaningful life. However, parents are confronted with the task of meaning-making concurrent with the need to actively make choices about how to best manage their personal and family lives. This brings us to the final transformative process: choice-making.

Choice-making: Responding to the "how should we live?" question. Following diagnosis of disability, parents are left with questions about how they will manage their lives. A substantial amount of psychological research contends that one's perception of personal control over one's circumstances, or locus of control, is related to positive outcomes (cf., Antonovsky, 1993; Meichenbaum & Fitzpatrick, 1993; Rimmerman, 1991). Assuming and maintaining personal control is also considered a characteristic of resilient individuals (Barnard, 1994; Brooks, 1994, Grant et al., 2003). In fact, Janoff-Bulman (1992) contends that a sense of personal control is one of the key variables that differentiates victims from survivors.

However, many parents of children with special needs assert that the majority of decisions regarding the education of their children are still being made by professionals, leaving them marginalized, and even alienated, by the "system" (Scorgie et al., 1999; Soodak & Erwin, 1995; Valle & Aponte, 2002). Parents often feel forced to assume "passive" roles, becoming "the recipients of information rather than the providers" (Garriott, Wandry, & Snyder, 2000, p. 42). Some have described encounters with professionals who treat them with condescension, even suggesting that their goals for their children are "unrealistic, unreasonable, and/or incompetent" (Soodak & Erwin, 1995, p. 271).

Nota et al. (2003) asserted that, rather than being in the "grip of despair" following diagnosis, most parents are active agents in the adaptation process, seeking out new ways of coping with daily circumstances. According to Turnbull and Turnbull (2001), parents desire control or ownership over the decision-making process regarding their children, which for many means preserving personal and family values and goals over and against conflicting goals of various agencies and institutions. In fact, the importance of choice-making in transformation might actually be the effect it has on the other two processes. When parents feel in control, they may be more able to fashion hopeful child, self and life-trajectory images. However, the degree to which the external impinges on choice-making may affect the formation of transformation. For example, parents who value inclusion may have wide opportunity for choice-making and control when their child is younger and inclusion is more straightforward. However, if inclusion is no longer an option given to the parent as the child approaches high school, the denial of choice and control may produce corresponding changes in child, self and life-trajectory images. Additionally, at this time the parent may be forced to come to terms with the differences between his/her child and typically developing children, which also may affect formerly held images and meanings. Thus, while having choice and control is important for overall adjustment, the main role of choice-making in transformation may be its effect on the other two processes.

Environmental influences

Constructing hopeful child, self, and life-trajectory images and meanings does not take place in isolation. Rather, it occurs within a specific environment, or perhaps even within a number of overlapping environments, in which the parent and family operate. Parental responses to diagnosis of disability can be profoundly shaped by the images hospital personnel, agency workers, educators, extended family members and friends construct of disability, the meanings they ascribe to "being disabled" and the choices they afford persons with disability and their families (Scorgie & Sobsey, 2000; Taanila et al., 1998). While environmental influences do not determine the content of images and meanings, they do reflect a socially-constructed network of shared knowledge, values and norms that define typical action (Hodkinson & Sparkes, 1997). Transformation may result from the necessity of parents to transcend stereotypical images and meanings they are confronted with and to make choices that override existing affordances.

Case Studies

The following three case studies, with names changed to respect confidentiality, have been selected from our ongoing qualitative research with parents of children with disabilities to illustrate the cross-cultural utility of the processes of image-making, meaning-making and choice-making. Interviews of approximately one hour in length were conducted between 1994 and 2002 and transcribed by the first author. Interviews followed a narrative format, beginning with diagnosis (e.g., "When did you first discover [your child] had a disability?") and reviewing family life experiences to the date of the interview. Probes were designed to explore family life management strategies, parental characteristics, and the experience of transformation.

Lamont (interviewed in 2002) is an African-American father of four children. At the time of the interview he was retired from a metropolitan police force and employed at a high school. His wife also worked full-time. Lamont began by describing his reluctance to have his ninth grade son, Terrence, tested for a learning disability (e.g., "The only thing that makes a disability worse is the perception of the disability. I thought--it couldn't be my son. My son couldn't be that way"), an unwillingness that he believes is common to fathers (e.g., "Men need to check their egos at the door. . . It's got to be about the child. You've got to let go of those barriers because it's not about you"). He asserted that diagnosis of disability is "a double whammy" for a child—first because the child has difficulty learning and second because of the "stigma" attached to special education in schools (e.g., "There's a big special ed stigma and the only way it's going to go away is if the administration starts recognizing that they have a stigma here"). Lamont spoke strongly of the importance of moving beyond the "Why?" question (e.g., "Sometimes things happen. There's nothing you can do about it. You can't explain it"), and instead focusing on how to help the child (e.g., "[You've got] to find out everything you can . . . things you can do to help him, and then reach for all the help you can get").

One thing Lamont described as particularly difficult for him as an African-American father was that special education classrooms were located at the back of the high school property (e.g., "Why do we put them in a little trailer in the back of the school? They're only punishing the kids"). The fact that students in special education classes were not given ballots to vote for prom king and queen, and were not members of school clubs or invited to be cheerleaders further isolated them and intensified the stigma attached to special education at the high school. His dream was to see every child have an equal opportunity for inclusion (e.g., "Imagine what it would do for the special ed program if they had a cheerleader or if they had somebody just to represent that they're OK. That would open up so many doors").

Lamont asserted that parenting Terrence helped him develop as a person (e.g., "I became more secure about me. That made me a better person") and taught him the importance of focusing on the positive aspects of life, both for himself (e.g., "I want to enjoy life—to enjoy every chance I get"), and for Terrence (e.g., "As long as he's happy . . . That's what it's all about"). He no longer defines success as an outcome (e.g., "making money"), but instead focuses on personal progress (e.g., "I told him, 'Just do your best. Do your homework. Participate.' As long as he's out there trying, that's all right with me"). The biggest difficulty for Lamont has been to transcend the restrictive images, ascribed meanings and limited choices afforded to students with disability at the school in which Terrence was enrolled. Ultimately, to Lamont, the real issue was one of human rights (e.g., "A student should say, 'If I go to [this] school, I deserve every bit. Not just a little bit, but every bit. It's supposed to be about freedom, right?").

Diane (interviewed in 1994) is a Canadian mother of a son, Chad, with Down syndrome. At the time of the interview she lived with her husband, son (15 years of age) and three other children. Diane's interview began with a powerful description of Chad's diagnosis shortly following his birth. Diane was alone in her room when, she reported, the physician ". . . arrived, stood in the doorway and said, 'There's something wrong with your baby. He's a Mongoloid idiot. Give him up. Don't ruin your life.'" Immediately confronted with negative images and meanings and a choice that she rejected, Diane acknowledged that her initial mistrust of professionals was further shaped when a social worker arrived the following day with adoption placement papers ready for her signature. Though Diane struggled initially with "Why?" questions, a turning point came when she joining a support group for parents of children with a variety of disabilities (e.g., "I'd see these other moms . . . laughing. It was just like, life goes on. It was a real eye opener for me").

From Chad's birth onward, Diane claimed ownership, first assuring early intervention programming (e.g., "I was one of the moms who got busy and made sure there was going to be a program") and later overruling the educational system to obtain an inclusive school placement (e.g., "the principal, the special education coordinator and the teacher . . . were there to tell me that that wasn't the best place for him--that I was irrational and that I was a bad mom"). Throughout Chad's public education, Diane upheld his right to inclusion (e.g., ". . . disability should not isolate him"), describing both herself and Chad as "pioneers." Clarifying her role as Chad's mother, not his therapist or teacher (e.g., "I learned to say 'no'"), was important to Diane's own image-making.

When asked how parenting Chad had changed her, Diane asserted that she had become more self-confident (e.g., "I have become more willing to take a stand. Before, I felt voiceless, but then I recognized that I am the only voice [Chad] has, so I learned how to use mine") and fulfilled (e.g., "I went from seeing myself as not having a lot to give the world, to having a new world—a world of advocacy"). Parenting Chad also produced a new perspective on persons who are devalued by society (e.g., "Chad has taught me that each person has something to offer the world. There are no throw-away people. Our society throws some people away. But everyone has something to offer"). She also gained new perspectives on what is important in life (e.g., "It's not how much we have that's so important. It's what we make of each day") and of living in community (e.g., "I had rebelled at the idea that [Chad] had to be dependent. But then, I thought, he's really interdependent, like we all are"). Diane shared a number of accounts describing how her life had been enriched through advocating for inclusive services for persons with disability and their families.

Isabel (interviewed in Spanish in 1999) lived in Tijuana, Mexico, with her five children, including Luis (5 years of age) who has profound hearing impairment. Divorced earlier from Luis' father, at the time of the interview Isabel was married to the father of her youngest child. Isabel began the interview discussing events surrounding Luis' diagnosis. When Luis was eight months old, Isabel realized he did not respond to loud noises and took him to a specialist who stunned her with a diagnosis of deafness (e.g., "I thought, 'I have a deaf child. How can that be?' I felt helpless. It was hard for me to accept"). Luis' father went into denial (e.g., "He never accepted it. He always says that Luis is not his son. I think he feels shame") and the two separated several years later.

Finding few local resources, Isabel took Luis for therapy to "a group of volunteer doctors from the U.S." and, at the time of interview, was part of an organized group of parents lobbying for better local services for children with hearing impairment. Though Isabel still had “Why?” questions (e.g., “Sometimes when my son is screaming and crying I don’t know why this has happened to me”), she finds comfort in her strong faith (e.g., “God showed me he gave me Luis, who is a special son, not a problem. He knew I could handle this”) and in her belief that everything in life has a purpose (e.g., “Sometimes I break down. Then I stand to my feet and say, ‘Everything that comes our way in life has a purpose’”). She stated that it was important for parents to accept the diagnosis (e.g., “In order to resolve problems, it is necessary to accept there is a problem and face it. My child is deaf. Now we are going to focus on resolving the problems”). She affirmed that it was important to focus on a positive future (e.g., “It’s important to say, ‘My child has a future.’ My son has as bright a future as anyone else”) and she valued the role she has played in helping other mothers (e.g., “I realized I could share with others what I learned. I can tell mothers I know what [they] are experiencing because I have been there”). She believes Luis has much to give to others because “he can give love, which is the most valuable thing you can give.”

When asked how parenting Luis had changed her, Isabel remarked, “He has given me the strength to move forward and have a purpose in life.” Her goal is to continue to learn sign language so that she can teach other parents and children. She has also become a more positive person (e.g., “I used to be a very negative person. He has made me look at the bright side of life. It has cost me because it is painful, but it is also beautiful to see things from the other side”).

These three parent interviews illustrate that parents enter the period following diagnosis with many questions. They were also immediately confronted with ways in which images had been constructed, meaning ascribed, and choices afforded to them and their children through the larger environment. And they utilized the processes of image-making, meaning-making and choice-making to resolve their original questions and move forward. In the process, each also experienced transformation of self and perspective.

Attestations of transformation are evident in the literature. Additional research, however, is needed to examine the role of professionals in promoting transformation in parents of children with disabilities.

Reflections and Implications

There are a number of important implications from the study of transformation that bear mentioning. First, it is clear from research that the experience of transformation does not require the absence of stress. On the contrary, positive transformations seem to occur in the midst of stress, pain and difficulty. While on the one hand confusing, this concomitant relationship between stress and transformation illustrates that the presence of stress and difficulty is not always indicative of maladaptive functioning. In addition, the goal in family intervention need not be to achieve absence of stress, if that were even a possibility. Rather, the goal should be to facilitate hopeful images and meanings and to foster a sense of parental choice and control.

Secondly, it might be argued that the experience of transformation is strongly linked to parent personality type or temperament, and there may be some truth to this statement. However, the overwhelming number of parents in our and other studies, who attest to transformation, makes it highly unlikely that personality type or temperament alone can account for the experience. Additional studies, however, are needed to confirm this hypothesis.

Thirdly, any conception of transformation must account for ongoing process. As Bloomer (2001) states, "Transformation is at least partly an uncertain process. It is seldom uni-directional, never uni-dimensional, only partly predictable and never complete" (p. 444). Our model supports the ongoing nature of this process and accounts for the fact that images, meanings and choices may have to be reconstructed across time.

Finally, the powerful effect of external influences on the processes of image-making, meaning-making and choice-making cannot be ignored. Disability is depicted through socially conscribed images and meanings. When parents are faced with professionals who view having a child with a disability as a catastrophe, constructing new images and meanings is made all the more difficult. Perhaps, then, it is imperative that professionals examine the images they have of parenting children with disabilities, the meanings they ascribe to disability and its impact on life, and the choices they and their organizations proffer to parents and families. For it may be that only those professionals who have hopeful images and meanings about disability, and who willingly share control of decision-making, will be able to enter into transforming partnerships with parents. And might it also be possible that through such a partnership they might be transformed as well?

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