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Hope in Families of Children with Developmental Disabilities

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Abstract

The focus of this study was to explore and understand the experiences of hope in families of children with disabilities. Based on a qualitative research design, nineteen parents participated in this study. Eight common themes have been identified within participants' descriptions during the process of data analysis. Hope has been identified as a positive transformation and dynamic process that helped parents to reframe their lives in view of their experience with children with disabilities.

The way families deal with the experience of childhood disability has been the focus of diverse studies in the past two decades (Barnett & Boyce, 1995; Donovan, 1988; Gallagher & Vietze, 1986). Although stress and despair are frequently reported as a problem for families having children with disabilities (Cameron, Dobson & Day, 1991; Dyson, 1993; Harris & McHale, 1989; Krauss, 1993), more recent researchers, along with many families themselves, have rejected these negative notions (Helff & Glidden, 1998; Sobsey, 1995; Stainton & Besser, 1998). Although many parents have reported positive changes, little research has been carried out to understand this positive adjustment to parenting a child with a disability or to determine how it can be promoted.

Hope has been found to be an important and a strong predictor of parents' acceptance of their child's disability (Juvonen & Leskinen, 1994). It has been identified as a life instinct, a complex intangible in the healing and coping process, and a prerequisite for effective coping (Jevne, 1991; McGee, 1984; Menninger, 1959). Despite increasing interest in the concept of hope, the nature and function of hope in the area of children with special needs have been neglected in the professional literature.

There have been few studies that have focused on the positive experiences a child with significant disability may generate within a family (Abbot & Meredith, 1986; Glidden, 1993). In one study of parents of children with disabilities, parents were reported to feel a greater power to achieve their goals, an increased ability to see life from other people's points of view, more compassionate, and stronger (Scorgie, 1996). These positive experiences appeared to enable parents to better meet the needs of their children with disabilities. Sobsey (1996), however, suggested that more research needed to be done with a wider variety of families before we can generalize these findings.

The purpose of this study is to explore and understand the experience of hope for families of children with significant developmental disabilities, and to identify the circumstances that facilitate hope. It is assumed that if more could be understood about the way in which family members cope and develop their perspectives as they live with the situation of a child with disability, it would be possible to identify strategies that could be used by health care providers and related professionals to enhance hope in the members of a family challenged by a child's disability. The strategies would then be driven by the actual experiences of those living with the situation rather than by a professional determination made at a distance from the experience.

Method

Procedures

A qualitative research design, using a case study approach, was used due to the exploratory nature of this study. Such a design has been recommended for researching relatively unexplored topics such as hope (Farran, Herth & Popovich, 1995; Field & Morse, 1985). Case studies are particularistic, descriptive, and heuristic in that they rely heavily on inductive reasoning in the handling of multiple data sources. The case study method does not claim any particular methods of data collection or data analysis (Mirriam, 1988; Yin, 1989). A collective case study is an instrumental study extended over several cases to manifest the common characteristics. In the study under discussion here, a collective case study approach, extended to several cases, was selected to better understand the experience of hope in parents of children with disabilities.

Participants and Data Collection

Two types of interviews were used to increase the diversity of the study participants: face-to-face interviews and internet interviews. Parent participants for the face-to-face interviews were contacted through various service associations, rehabilitation centres, and community members. These interviews were conducted after having obtained written consent from the potential participants. To recruit parent participants for the internet interviews, details of the study were posted on the internet along with the interview protocol and instructions for potential participants. The internet participants responded according to the interview protocols on the internet. A total of 19 parents participated in the study. Eight parents participated via face-to-face interviews and 11 parents responded to the interview protocol via the internet. The internet posting helped to achieve diversity of experiences, age, education, religion, and country of origin of the participants. Overall, children of the participants ranged in age from 3-18 years, and presented with a variety of disabilities (Down syndrome, autism, Joubert syndrome, muscular dystrophy, and Asperger syndrome).

An interview guide was prepared by the investigators as a framework for the data collection. The following questions were asked of the parents to explore hope in their experience of having special needs children.

1. Regarding your experience as parent of a child with disability, what does hope mean to you?
2. What would I need to know about you to better understand your feelings about hope?
3. Can you think of any events that have either enhanced or diminished your feelings of hope?
4. Can you think of any things that family and friends did that made it harder or easier for you to be hopeful in regard to your child? If so, what were they?
5. Can you think of any things that professionals or service providers did that made it harder or easier for you to be hopeful in regard to your child?
6. Is there anything you do on regular basis that strengthens your feelings of hope?

Face-to-face interviews were audio taped with the prior consent of the study participants. Interviews were transcribed and analyzed using a constant comparative method of coding and categorization (Glaser & Strauss, 1967). At first step, an individual case analysis was done to understand each case by searching for individual patterns and themes. Secondly, a search for patterns across-cases was conducted to identify common themes in the data. There were no preconceived ideas into which the data were structured to fit. Alike responses of participants helped to determine the definition of a category. Inter-coder reliability (common findings of the data analysis conducted by more than one person) added rigor and trustworthiness to the findings. In this study, constant comparative methodology helped to identify eight invariant themes of hope.

Emergent Themes

The analysis of parents' interviews revealed that each family's experience of having a child with a disability is unique in light of their specific circumstances, the nature of the child's disability, and available resources and support for the family. The initial experience was described as frustrating, shocking, and challenging, but this experience evolved into emotional strength, meaningfulness in life, and personal growth with the passing of time. Not surprisingly, hope was threatened when an unexpected future was presented. A mother of a daughter with Down syndrome expressed her initial feelings of shock followed by strength:

> *When she was born I was not expecting a baby like her and you know...no one expects things like that. I had already two healthy babies and when she [doctor] told me about her condition...I went into shock. It was the most difficult time of my life. In the presence of others I used to feel myself strong but...while alone...I used to cry a lot...but this period did not prolong much. I felt myself stronger and stronger with the passing of days.*

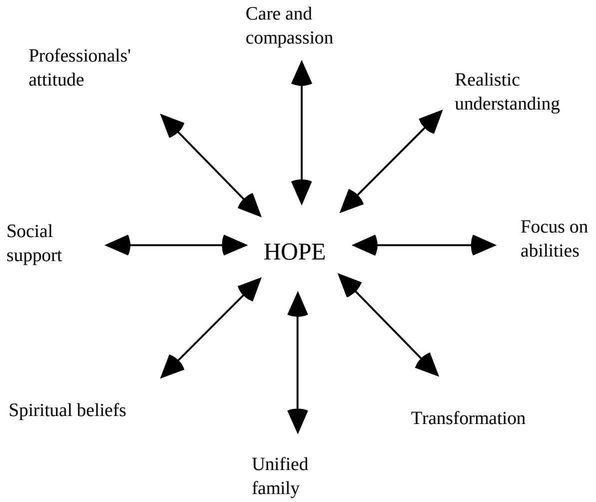
However, many elements of the experience of childhood disability were common among most, or all, of the participants. The following eight themes were identified as experiences of hope derived from the data provided by the parents' descriptions of their personal experiences of having a child with a disability (see Figure 1).

1. Care and Compassion

Parents' narratives reveal that their experience of having a child with a disability enabled them to feel compassion, love, care, and value for life. The experience reportedly enriched their lives. As a mother of a child with autism narrated:

> *I remind myself that every human life is valuable and important, that people who are nonverbal "have a lot to say," and that my son's autistic perspective is as valid as my non-autistic perspective, but it's different. I try to open myself up to just "being" with him (a state of relaxation, appreciation and acceptance).*

Figure 1: Emergent Themes



This particular theme revealed that, for the participants of this study, parenting a child with a disability helped to facilitate a hopeful attitude, empathy, love, and compassion in the families of these children.

2. Realistic Understanding

The second theme portrayed parental hope as including an acceptance of the reality regarding the child's disability condition. One father expressed his concern and understanding of his child's disability based upon realistic hope:

> *The most important thing in my life is that I ask my doctor what is his expectancy in life...whether he will be all right or he is gonna be a handicap throughout life. So my only hope is as long as he lives...he live a comfortable life...then I am satisfied. That's why I don't believe in things or do not hope something that is not possible so the hope was not dead but I accepted the fact.*

A set of parents with two children having significant disability spoke of the challenges and turning points in their lives. Their determination and hopeful perspective helped them in finding solutions.

> *All the way along over time, there were challenges that came up with both boys, but we always believed that there were solutions to those challenges. We were always looking for the answers to those challenging questions and challenging situations.*

These descriptions were regarded as evidence of the value of an approach grounded in reality for parents raising a child with disability. Parents' experiences in this study revealed that acceptance of the facts related to the disability and determination to provide a comfortable life to the child were assets stemming from having realistic hope.

3. Focus on Abilities

Most of the parents' responses shed light upon the idea that one source of hope was the abilities, rather than the disabilities, of their children. A mother attributed her daughter's innocent manners and selfless love as a source of inspiration for her:

> *There are so many other things...so many. Her good physical health, her talks, her loving nature, her smile, all these give me hope that she can live an independent life with some support.*

Another parent said:

> *...and then for two or three years she started to learn how to chew and it was...to think back on where she started from and to where she is now, is quite amazing.*

This theme reinforced the idea that a positive focus may lead towards hope and resilience in everyday life experiences for parents of children having disabilities.

4. Transformation

Parents experienced a positive personal transformation, enhanced personal resources, increased tolerance, and emotional stability as a result of their parenting a child with a disability. A father talked about his increased sensitivity and respect for life:

> *It strengthened my belief in myself…it has made me a tolerant person. I have become emotionally more stable and I can see that most of the experiences I have had a positive influence on me.*

Another parent gave the credit of her own growth to her daughter with Down syndrome:

> *In the very beginning, whenever I saw a healthy newborn baby I had a deep strange sense of loss that is not easy to describe but, now, I thank God for this blessing that enabled me to understand the reality of life.*

Parents' accounts provided credence to the view that a hopeful picture of the self was a reward of their interaction with their child. These findings provided a rare insight into the lives of those families who viewed the child as a gift within a growing and strengthening experience.

5. Unified Family

It was clear within parents' narratives that they understand their child's disability to be a source of unification and cohesion within the family despite challenging situations. One father delineated the sharing of family members:

> *My mother and sister, whenever they came, they appreciated and encouraged our commitment with the kids. We have an intact family and we basically share.*

For another parent, spousal support was a distinct coping resource to deal with the challenge of the child's condition:

> *I think that it's made my husband and myself closer. We celebrate her accomplishments with our extended family, parents, and in-laws. I guess it made us more conscious of things like quality family time and doing things together.*

The present theme supported the notion that spousal support and an extended family's positive attitude, sharing, and practical help was a source of hope and satisfaction for the parents' immediate family members.

6. Spiritual Beliefs

Spiritual beliefs and a sense of purpose in life offered a way for parents to define, or interpret, their child's disability in a positive way. Their philosophy of life and their faith led them to believe that they had been especially selected to provide comfort and care to the child.

> *I believe that you're never given anything in life that you can't handle, and, to some degree, I think there's always a purpose in life for everything. Maybe there was another meaning behind having a child with a disability, maybe it was so that later in life I would be a stronger advocate for other people as well as my daughter.*

A mother expressed her beliefs:

> *I feel that children are gifts and God doesn't make mistakes. In society's eyes she is not perfect but in our eyes, she's just as perfect as our son. We enjoy her accomplishments just as much as we enjoy our son's accomplishments.*

The parents' belief system and spirituality served as a coping resource for the challenge of rearing a child with disability and, for the families in this study, appeared to enhance and maintain hope.

7. Social Support

The availability of social resources and the sharing of common experiences was reported to be a major contributor to resilience and hope for the parents of special needs children in this study.

> *I get together with other parents who have children with similar diagnoses as mine and I find that that's very strengthening and positive to see other positive situations where their children are. It helps me keep on track.*

This theme indicated that parents of children with disabilities did not perceive themselves to be socially isolated. The social network of families sharing compassion and similar experiences was a strong support for them.

8. Professionals' Attitudes

A mixed reaction towards the attitudes of professionals was found in the descriptions of parents with special needs children reported here.

> *In terms of medical professionals, we had some situations that were just unbelievable, unbelievably bad, and some situations on the other hand that were wonderfully supportive.*

Some of the accounts indicated professionals' helping attitude in a time of need.

> *The clinicians, other health care professionals and handicapped children's services have been very helpful in providing information and other professional help to reduce the anxieties of the parents.*

This qualitative study revealed a mix of reactions among parents toward professionals that indicated professionals need increased sensitivity and empathic understanding within the realm of childhood disability.

Discussion

The findings revealed hope as a dynamic process that helped parents to reframe their lives in view of the experience of having a child with special needs. Most of the parents reported that accompanying a child with a disability on the road to life became a positive and strengthening experience for them. Findings also supported the recent research that having a child with disability contributed to personal and spiritual growth, family stability, and personal hopefulness (Behr & Murphy, 1993; O'Conner, 1995).

Though variability existed in the experiences of parenting a child with a significant disability (in view of many factors such as social support, philosophy of life, and the personal characteristics of the parents), the findings reported here reflected upon the brighter side of the picture. Parents' descriptions revealed how their own experiences with their child with a disability shaped their overall experience of hope in life. For the parents in this study, hope was strengthened by both their internal (belief system, motivation, rationality) and external (family, friends) resources. Parents recognized their inner potential, their hidden qualities that enabled them to deal with their child's disability. They reported having redefined and reframed their role as parents after the birth of their child with disability. This process provided them a sense of strength, transcendence, and meaning in life.

A mixed reaction toward family, friends, professionals, and community members was also found in this study. On one hand, family and friends' support enabled parents to better meet the needs of their child with a disability. As a result, parents developed a strong motive to share and celebrate the rewards of their children’s small gains with others. They frequently celebrated these gains with grandparents and extended family. On the other hand, service providers' and professionals' negative evaluations of the child's disability reportedly made parents feel hopeless for the child's future. Although parents negative experiences with professionals have been the focus of other studies, more research is required to determine the ways to increase positive and hopeful interactions between parents of children with disabilities and the professionals they rely upon for support.

Although positive experiences of disability are not ubiquitous in the special education literature, they do exist. Recently, Helff & Glidden (1998) reviewed family adjustment research over a 20-year period to determine the negative and/or positive conceptions of families rearing children with developmental disabilities. The authors found that there occurs a move from a less negative to a more positive portrayal of this group of families taking place in the literature between the 1970s and the 1980s/1990s. Although this change is not significant, it does reflect a shift in paradigms over time.

The findings presented here suggest that hope and positive transformation are meaningfully interconnected in the lives of parents of children with developmental disabilities, and that further research exploring the positive attributes of hope may be highly valuable for these families and for professionals in the field of special education.

References

Abbot, D., & Meredith, W. (1986). Strengths of parents with retarded children. *Family Relations, 35*, 371-375.

Barnett, W. S., & Boyce, G. (1995). Effects of children with down syndrome on parent's activities. *American Journal on Mental retardation, 100*, 115-127.

Behr, S., & Murphy, D. (1993). Research progress and promise: The role of perceptions in cognitive adaptation to disability. In A. Turnbull, J. M. Patterson, S. Behr, D. Murphy, J. Marquis, & M. Blue-Banning, (Eds.), *Cognitive coping, families, & disability*, (pp.151-163). Baltimore: Paul H. Brookes Publishing.

Cameron, S. J., Dobson, L. A., & Day, D. M. (1991). Stress in parents of developmental delayed and non-delayed school children. *Canada's Mental Health, 39*, 13-17.

Donovan, A. (1988). Family stress and ways of coping with adolescents who have handicaps: Maternal perceptions. *American Journal on Mental Retardation, 92*, 502-509.

Dyson, L. L. (1993). Response to the presence of a child with disabilities: Parental stress and family functioning over time. *American Association on Mental Retardation, 98*, 207-218.

Farran, C. J., Herth, K. A., Popovich, J. M. (1995). *Hope and hopelessness: Critical, clinical, construct*. Thousands Oaks, CA: Sage Publications.

Field, P. A., & Morse, J. M. (1985). *Nursing research: The application of qualitative approache*s. Rockville, MD: Aspen Publication.

Gallagher, J. J., & Vietze, P. M. (1986). *Families of handicapped persons: Research, program, and policy issues*. Baltimore: Paul H. Brookes Publishing.

Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory: Strategies for qualitative research*. London: Weidenfeld and Nicolson.

Glidden, L. M. (1993). What we do not know about families with children who have developmental disabilities: Questionnaire on resources and stress as a case study. *American Journal on Mental Retardation, 97*, 481-485.

Harris, V. S., & McHale, S. M. (1989). Family life problems, daily caretaking activities, and the psychological well-being of mothers of mentally retarded children. *American Journal on Mental Retardation, 94*, 231-239.

Helff, C. M., & Glidden, L. M. (1998). More positive or less negative? Trends in research on adjustment of families rearing children with developmental disabilities. *Mental Retardation*, *36*, 457-464.

Jevne, R. F. (1991). *It all begins with hope: Patients, caregivers, and bereaved speak out.* San Diego, CA: Luray Media.

Juvonen, J., & Leskinen, M. (1994). The function of onset and offset responsibility perceptions in fathers' and mothers' adjustment to their child's developmental disability. Psychosocial Perspectives in Disability [Special issue]. *Journal of Social Behavior and Personality, 9*, 349-368.

Krauss, M. W. (1993). Child-related and parenting stress: Similarities and differences between mothers and fathers of children with disabilities. *American Journal on Mental Retardation, 97*, 393-404.

McGee, R. F. (1984). Hope: A factor influencing crisis resolution. *Advances in Nursing Science, 6*, 34-44.

Menninger, K. (1959). Hope: The academic lecture. *The American Journal of Psychiatry*, 481-491.

Mirriam, S. (1988). *Case study research in education.* San Francisco: Jossey-Bass.

Oe, K., (1996). *A healing family*. Translated by Snyder, S. Tokyo: Kodansha International.

O'Conner, S. (1995). We're all one family: The positive construction of people with disabilities by family members. In S. J. Taylor, R. Bogdan, & Z. M. Lutfiyya (Eds.), *The variety of community experience: Qualitative studies of family and community* (pp. 67-77). Baltimore: Paul H. Brookes Publishing.

Scorgie, K. I. (1996). *From devastation to transformation: Managing life when a child is disabled.* Doctoral Dissertation, University of Alberta.

Sobsey, D. (1995). *Hikari finds his voice*. Compassionate Healthcare Network.

Sobsey, D. (1996). Family transformation: From Dale Evans to Neil Young. In Friedlander, R., & Sobsey, D. (November 13-16). Conference Proceedings: *Through the life span*, NADD.

Stainton, T., & Besser, H. (1998). The positive impact of children with an intellectual disability on the family. *Journal of Intellectual and Developmental Disability, 23*, 57-70.

Yin, R. (1989). Case study research: Design and methods. Newbury Park, CA: Sage Publications.

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