Between joy and sorrow: being a parent of a child with developmental disability

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Aim. This study explored the experiences of parents who have children with significant developmental disability.
Background. Prevailing societal and professional assumptions of parental crisis and maladjustment in response to the 'tragedy' of having a disabled child did not accord with the authors' practice experience. Whilst parents confronted numerous difficulties, most of them appeared to manage with optimism and remarkable resourcefulness.
Research design. The study, using an interpretive methodology informed by phenomenology, intensively explored the experiences of six parents of children with significant developmental disability.
Findings. Although they experienced much anguish and sorrow, the parents also spoke of hope, love, strength and joy. Interpretation of the parents' experiences revealed the themes of 'joy and sorrow', 'hope and no hope' and 'defiance and despair', mediated by 'the tensions'.
Conclusions. This phenomenological interpretation provides insight and understanding into the parents' experiences and has implications for practice, education and research in nursing.

Keywords: disability, child, parents, joy, hope, denial, chronic sorrow, nursing, health professionals

Background to the research

Western, success-orientated cultures place high value on intelligence, beauty and youth. According to Goffman (1963), people who are poor, ugly, crippled or unsuccessful are viewed as failures; they have a spoiled identity and are stigmatized. People with disabilities have long been viewed as burdens on society (Turnbull & Turnbull 1990), which generally views the presence of a child with a disability as a tragedy from which the family may never recover. This view is often mirrored by researchers, service providers and health care professionals whose task of family support becomes one of '…ameliorating the deadly pall of tragedy that hangs over the family' (Summers *et al.* 1989, p. 27).

The inevitably negative impact of disability on the lives of families is assumed by most, has dominated the literature and driven the research agenda for decades (Ehlers 1966, Featherstone 1980, Collins-Moore 1984, Sherman & Cocozza 1984, Chetwynd *et al.* 1986, Eden-Piercy *et al.* 1986, Blumel 1988, Erickson & Upshur 1989, Flynt & Wood 1989, Frey *et al.* 1989, Mercer 1990), leading researchers to focus on parental stress and the burden of care (Summers

1988). The research literature describes parental reactions of fear, denial, anger, frustration, guilt, grief and mourning following the initial impact of diagnosis of severe impairment in a child, summarized by Landsman (1998) as the 'trauma of dashed expectations' (p. 76). These are merely the beginning of chronic, relentless stress, accompanied by continued sadness and, consequently, ongoing distress and dysfunction in families is implicit (Beckman 1991).

Whilst the last decade has seen radical changes in the conceptualization and theorizing of disability (see Campbell & Oliver 1996, Hales 1996, Oliver 1996, Linton 1998, Shakespeare 1998, Barnes *et al.* 1999, Corker & French 1999, Drake 1999, Marks 1999, Priestley 1999, Thomas 1999, Swain & French 2000) and this is beginning to be recognized in some nursing literature (Northway 1997, 2000, Scullion 1999; Bricher 2000), the consequences for parents of disabled children have been limited because of the continuing dominance of medical discourse which views disability from an individual and tragic perspective. At the inception of this research there was an emerging literature that referred to 'positive contributions' to family life of a child with developmental disability (Turnbull *et al.* 1988, Turnbull & Turnbull 1990) and, since its completion in 1996, (Kearney 1996), there is evidence of a shift in research emphasis on the adjustment of parents (Helf & Glidden 1998) with more research reporting broader perspectives (Scorgie *et al.* 1996, Larson 1998, Stainton & Besser 1998, Scorgie & Sobsey 2000). However, this has made little impact in the nursing literature in which the tragedy, burden and pain of having a disabled child are implicit (Knafl *et al.* 1996, Browne & Bramston 1998, Monsen 1999, Glassock 2000).

As practitioners, nurses' expectations, drawn from theoretical preparation and experience, inform their interpretations of the lives of the people with whom they work. Traditional theoretical approaches that influence professional interpretation of parental responses to having a child with developmental disability are: Solnit and Stark's (1961) influential mourning the loss of the 'perfect child' which was adopted by paediatricians (Drotar *et al.* 1975); the pervasive time-bound models of grief and mourning (Lindemann 1944, Engel 1961, Kubler-Ross 1969, Bowlby 1980, Irvin *et al.* 1982) in which acceptance is central to healthy adjustment, whilst failure to accept loss is maladaptive and requires intervention; Olshansky's (1962) chronic sorrow, which contends that acceptance is not necessary for functional adaptation, and which has been widely adopted by nurse theorists and researchers (Damrosch & Perry 1989, Fraley 1990, Clubb 1991, Phillips 1991, Teel 1991, Lindgren *et al.* 1992, Johnsonius 1996, Eakes *et al.* 1998, Krafft & Krafft 1998, Mallow & Bechtel 1999); and classic psychoanalytic theory which influences professional interpretations of parental responses as neurotic defence mechanisms of denial, projection, repression, displacement or sublimation (Brown 1993).

Uncritical application of these theories in the interpretation of the behaviour of parents of children with disabilities has negative implications. Parents, for instance, can be labelled as responding pathologically. It is not unusual to hear professionals use expressions such as: 'They're not being realistic'; 'They won't accept the child'; 'They're shopping around, looking for someone who'll say there's nothing wrong'. When professionals interpret parents' words and behaviours as denying reality, rather than demonstrating the ideals of 'acceptance' and 'being realistic', the parents may be viewed as dysfunctional.

The first author's community nursing practice with about 200 disabled people and their families resulted in a dissatisfaction with prevalent interpretive paradigms and led her to question the conceptual base for the impact of disability on the lives of families. Families generally managed their lives cheerfully and constructively and, although there was pain, they mainly dealt with it. Some parents made an enormous impact by their energy, strength, optimism and humour. One parent, Amanda, who was remarkably optimistic and insightful despite enormous and persistent difficulties, provided the key for the research project. In recalling the frustrations following the birth of her daughter, Annie, she said:

> I knew her condition was serious and her prognosis poor but, to me, she was my firstborn, beautiful child. Every time I expressed my joy to the staff at the hospital, they said, 'She's denying reality'. I understood the reality of my child's situation but, for me, there was another reality.

It was Amanda's 'other reality' that gave this research a voice and became the focus of the research endeavour. Following is a report and discussion of the research.

The study

Research design

A qualitative, interpretive research approach, driven largely by Van Manen's (1990) eclectic hermeneutic phenomenology, provided a methodological structure for a principled enquiry of lived experience. The focus was the 'interpretation of the experience from the individual's unique perception of…event(s)' (Munhall 1994, p. 16). This gave the parents the control and freedom to explore the meaning of their experiences and moved away from previous work that had focused on specific aspects of experience such as grief, stress and the burden of care.

Ethical considerations

Following approval from the ethics committee at the University of Western Sydney letters were sent to 12 parents with whom the first author had previously worked and who had expressed interest in ongoing contact for the purposes of research. Comprehensive information sheets which outlined the nature and purpose of the research, along with issues related to consent, confidentiality and the right of withdrawal, stated that the research was about 'parents' experience of developmental disability' (Kearney 1996, p. 241).

Because of the first author's prior practice experience with these families, care was taken to ensure that pressure was not exerted. The information was sent to parents requesting them to return a tear-off slip if they were interested in participating in the project. Ten replied and expressed enthusiasm for the project when subsequently contacted by telephone. However, because of time constraints and density of data, only six parents were interviewed. Pseudonyms are used throughout.

Box 1 Details of study participants at time of initial interview

Jill and John, parents of Joel, had one younger daughter.

Joel, 4 years – brain damage due to near drowning at 2 years. Parents were advised that he would be a 'vegetable' if he survived. Interactive and happy child with major motor impairments; cognitive status unknown, but saying a few words.

Sally and Stephen, parents of Samuel, had six older children.

Samuel, 4 years – brain damage due to meningitis at 7 months. Was expected to die, then parents were told he would 'do nothing'. Very active child with mild hemiplegia, cortical blindness, seizures, severe global delay (with exception of gross motor skills), no speech and minimal interaction with others.

Amanda, mother of Annie, was divorced.

Annie, 6 years – congenital impairments due to probable intrauterine viral infection. Initially failed to thrive, was not expected to survive and parents were advised that 'there was nothing to be done apart from loving her'. Tiny, happy and highly interactive child with global developmental delay.

Catherine, mother of Charles, was separated.

Charles, 3 years – has Down's syndrome. Had a 'wait and see' prognosis. Relaxed and amiable little boy with global developmental delay including significant cognitive impairment and motor difficulties.

Methods

Participants

Six parents, two couples and two single mothers, spoke intimately and at length about their experiences during a series of interviews. Brief details of the participants and children at the time of initial interview appear in Box 1.

Data collection

Whilst the generation of data and their interpretation were concurrent and ongoing processes, the procedures will be described separately.

Experiential descriptions from the parents. Discussions with parents took place over a period of 18 months and were mostly face-to-face conversations. Some discussion, postinterview, took place over the telephone, generally as a need to clarify a point or to discuss a researcher's insight. All face-to-face discussions were audiotaped, whilst notes were made of telephone conversations. Initial interviews, lasting 2–3 hours, were individual, but subsequent joint interviews were completed with the couples. All were interviewed in their own homes, with the exception of Sally and Stephen who chose to come to the researcher's home. Contextual notes were made following the interviews.

At the beginning of each initial interview, parents were asked, 'Can you tell me about your experiences of living with (name of disabled child)'. Whilst the research hoped to uncover the 'other side' of their experience, Amanda's 'other reality', care was taken to diminish researcher influence on the parents' recollections. The parents had the freedom to speak from their own perspective and to tell their stories. They all went back to the 'beginning' and told their stories as temporal narratives from either the birth of the child when impairment was apparent (Amanda and Catherine), or from the time of the child's illness or accident which resulted in impairment. Generally, about half the discussion time was spent on these narratives, during which the parents referred to many negative aspects of their experience. This seemed to act as a cartharsis, and was followed by conversation that focused more on their children and what was occurring in the present.

Experiential descriptions from other sources. Parents' experiences, from a variety of sources such as books, magazine and newspaper articles, and film, as well as fragments from professional literature sometimes provided interpretive insight. In keeping with Van Manen's (1990) research approach, increasing sensitization to the project resulted in insight coming from multiple sources and, as time progressed, the emerging interpretive lens was applied to 'thicken' categories.

Box 2 van Manen's (1984, 1990) analytical processes

- Examination of individuals' experiences
- Uncovering thematic aspects
- Development of structures of whole phenomenon
- Conversational reflection with participants to refine themes
- Thematic description from other sources
- Determination of essential themes
- Writing
- Presentation of work to audiences
- Rewriting
- Refinement

Data analysis

Analysis consisted of van Manen's (1984, 1990) phenomenological reflection, interpretation and writing, as found in Box 2.

The discussions with parents were transcribed and contextual annotations were added. Transcripts had multiple readings prior to detailed substantive coding, which we termed 'response coding'. These codes were then indexed against various starting categories, such as 'feelings', 'values and beliefs', 'attitudes', 'behaviours', 'people', 'child', using NUD.IST software (Richards & Richards 1990) to support the management, exploration and interrogation of data. Over a period of time, patterns in the expanding coding system became apparent, allowing for a reconceptualization of the data into fewer, but denser categories. Themes were developed as a conceptualization of the relationships between many of the categories and subcategories, 'moving the descriptions away from the particular to a more universal sphere' (Morse 1994, p. 36). A model of the main themes and their interrelationships was developed to facilitate a visual recognition of the gestalt of the phenomenon, along with its component parts.

Some subsequent discussion with participants was recursive, checking for intent and validation; ideas and hunches were explored with them resulting in some being discarded. Whilst initially, Husserl's (1970) notion of bracketing had appeal because of the researcher's commitment to exploration from the parents' perspective, the parents themselves did not 'bracket' interpretations and sometimes referred to things such as 'staged grief' and 'the grief process'. This is in keeping with the Heideggerian notion of persons existing in and of the world, in which we are essentially cultural creatures existing in a world of taught meanings and significant symbols (Crotty 1996).

The emerging interpretation was presented at colloquia and conferences and was meaningful to professionals in the field, some of whom were also parents of disabled children. The final interpretation received the 'phenomenological nod' from the parents: 'Yes, I like that'; 'You've put it very well'; 'Yes, very much so'.

Findings

The interpretation of the parents' experience took shape in light of the major themes of 'joy' and 'sorrow'. However, this interpretation was too static and did not account for the ambiguity which is intrinsic to the parents' experience. A model was developed in order to visualize, clarify and tease out elements of a phenomenon that is dynamic and complex. Although necessarily a simplified representation of the parents' reality, the model in Figure 1 provides us with a 'universal skeleton' (Swanson-Kauffman & Schonwald 1988, p. 104). Through the conceptual lens of 'the tensions', the model illustrates the undercurrents of 'confusion, doubt and ambiguity' along with the dynamic interaction of 'joy and sorrow', 'hope and no hope', and 'defiance and despair'. It depicts the state of joy as deriving from the parents' relationships with their children, whilst sorrow is a frequent response to the parents' dealings with other people.

The themes are not to be viewed in isolation, but rather grasped and understood within the context of the whole phenomenon of 'between joy and sorrow'. They should be viewed as parts of a dynamic whole which shift and merge and are interwoven to the degree of becoming dependent on each

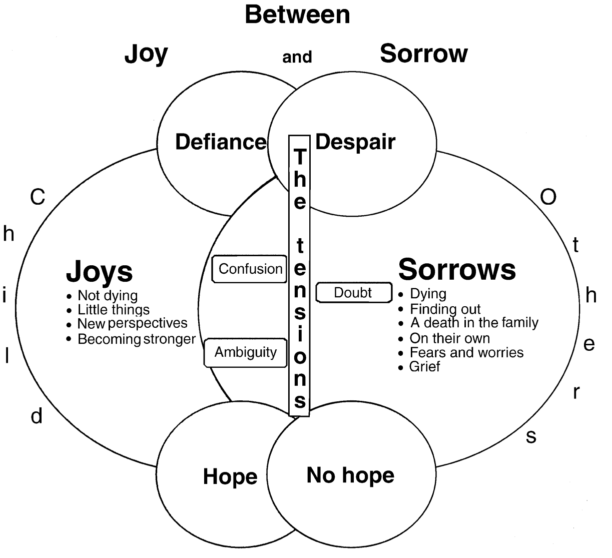

Figure 1 Between joy and sorrow: being a parent of a child with developmental disability.

other for their existence, as in Amanda's words: 'The joy is defined by the sorrow which has come before'. The parents' experience is one of paradox and ambiguity and is fraught with conflict and confusion. A brief overview of the major themes, along with their contributing elements, is now presented.

Sorrow

A number of elements contributed to and were part of the parents' sorrow. Although their biographies and situations were individual, there was a shared consciousness of sorrow to which the following contributed: the anticipated possibility of the child *dying*; *finding out* about the child's changed potential; being treated as if there were *a death in the family*; being left *on their own* by other people and the health system; *being vulnerable* as public parents (see Darbyshire 1994) and feeling powerless; having many *fears and worries*, particularly for the future; and a perplexing and complex *grief*.

Much of the parents' sorrow derived from their dealings with other people's frequent messages of negativity and hopelessness. Some participants reported instances of perceived hopelessness that led to despair. It was these issues which resulted in the themes of 'other people' and 'no hope and despair'.

'Other people'

The parents all painted an initial, overwhelming picture of negativity, which continued to be reinforced. They were inundated with negative messages from 'other people' – from professionals with their hopeless prognoses, along with families and friends, all of whom were responsible for feelings of isolation, rejection, anger, hurt, failure and despair. For example:

> …so much writing off, so much rejection. Yes, yes you have given birth and this is actually a reject child. 'Try for another one' they say almost immediately. (Amanda)

> …after he had come out of the coma, we were hit with the fact that he was 'going to be a vegetable' (Stephen).

'No hope and despair'

All of the parents spoke of messages of 'no hope' being imposed upon them and were angry about a professional approach which left no room for hope.

> …'he won't do this', 'he won't do that', 'no, we can't do anything for him'…I don't thing anybody has the right to take away everything which is what happens just too many times. (Sally)

There are instances of the parents being immobilized by their despair, of them feeling utterly helpless and powerless. Jill 'needed to be swallowed up in a hole' when it was thought Joel would die, and when he first came home from hospital she

> '…just sat there and cried and I just sort of said, 'I just don't know what to do'…It was sort of like despair, you know, 'What do you do now?'

The sorrow, which emerged from the parents' stories of their experiences, is congruent with traditional assumptions. There is for them, however, another reality largely ignored in the professional literature: joy.

Joy

In an apparently contradictory manner (if one considers 'sorrow'), the parents emphasize their experience as being positive. They believe they are 'better people' and have been 'strengthened'. John goes so far as to say, 'I wouldn't miss what I've been through for anything'. Themes which contributed to the parents' state of joy are: their children not dying; the little things that their children do; new perspectives following overwhelming changes in personal beliefs and values; and becoming stronger in the face of adversity.

Despite the odds and negative attitudes, along with prognoses that their children would 'do nothing', the parents maintained hope, struggled to ensure their children's survival and development, and spoke of them with admiration, love and optimism. These factors led to the themes of 'the child' and 'hope and defiance'.

'The child'

When speaking with the parents, it was clear that their children were a source of joy. They were animated and enthusiastic when recounting events, and their voices were full of pride and love. They spoke of their children in glowing terms and used words such as: 'beautiful', 'affectionate', 'generous', 'cheerful'. They claimed their capacity to keep going in the face of sometimes overwhelming negativity was because of the inspiration they derived from the children who were described as 'fighters', 'survivors' and 'gutsy'.

> 'He's got my admiration. Something I would like to have is the guts he's got.' (John)

'Hope and defiance'

Although they were conscious of the limitations of their children, the parents in this study tried to keep hope alive. Their stories abound with a sense of optimism and hope for the future, leaving them open to accusations of 'denial of reality' and 'nonacceptance'. All the parents appeared to have a firm grip on reality. They demonstrated a clear and informed understanding of their children's impairments and possible functional outcomes. However, they still maintained hope, which we define as ‘a belief in possibilities’ (van Manen 1990, p. 123). Their hope is akin to dreams; expectations are more real with objectives in mind, and were not part of these parents’ vocabulary. Not having a map, they have learned to live without expectations, but said they could not function without hopes and dreams.

> …a little bit is better than nothing, and you have to have some sort of goal or dream to work towards. I mean everything in life is, that has been done, has been done with a purpose or a dream (John).

Cousins (1989) questioned whether people with life-threatening illnesses who were seen as inappropriately optimistic were ‘denying reality’. ‘They didn’t deny the diagnosis; they denied and defied the verdict that was supposed to go with it’ (p. 83). This statement led to the theme of ‘defiance’, which provides a positive, action-orientated re-conceptualization of words and behaviours that have traditionally been interpreted as pathological. Defiance of their children’s prognoses enabled the parents to function with hope and optimism and to carry out therapeutic regimes which would be pointless if they paid heed to the predictions of ‘will do nothing’ and ‘will be a vegetable’. Catherine responded to the developing interpretation of ‘defiance’ in the following way:

> …focusing on ‘can’t do’s’ leads to a heavy sense of climbing the mountain which results in parental impotence. I’m not denying reality – I just don’t want to feel heavy all the time.

The joy derived from their children is central to the parents’ reality. Why then do professionals often neglect it? Perhaps because the joys are often ambiguous and the parents’ experience often one of conflict and paradox; their experience is modulated by the tensions.

The tensions

An interpretation of ‘joys’ and/or ‘sorrows’ did not take account of the ‘confusion, doubts and ambiguities’ that are also intrinsic to parents’ experiences. Rather, it was as if these states were held in tension and were mediated by confusion, doubt and ambiguity; hence arose the notion of between joy and sorrow.

The parents spoke of: confusing and conflicting emotions, information and advice; ambiguous prognoses; of their own observations being in conflict with the information they were being given; of not knowing what to expect and sometimes, of simply not knowing what to do. They had entered a world in which they had no experience and no knowledge, and there were no signposts or maps. They were torn by joy in the survival of their children but, at the same time, questioned the cost. They recognized the children were lucky to be alive but, in the same breath, expressed their sorrow at what they were missing out on. Some grieved for the loss of the children as they knew them and, at the same time, felt unjustified in their grief as these children continued to exist. They described their children in glowing terms whilst recognizing that, prior to their experience, they did not value people who are like their children, that they were afraid of them and had little to do with them. Their assumptions were being constantly challenged, and this made for a powerful and conflicting undertow – an undertow that acts as a tension between the experience of joy and sorrow.

Also contributing to the concept of tension was the seemingly paradoxical nature of the parents’ experience. All parents expressed, in some way, the existence of joy because of the pain, which Jill captured:

> And you’re a million times more happy because he’s done it, because he wasn’t supposed to be able to do it.

Reflections on the study

It is not surprising that pain and sorrow are integral to the experience of being a parent of a child with significant impairment. However, the contribution made by others to their sorrow was unexpected. Parents presented an initial overwhelming reaction of ‘no hope’. It was clear that they were being inundated with messages of hopelessness from other people and that professionals contributed to these feelings (see also Stainton & Besser 1998). Developmental disability holds a multiplicity of negative meanings, resulting in societal attitudes and practices that are dehumanizing (see Blatt & Kaplan 1966, Wolfensberger 1969, Blatt 1970, Menolascino 1977, Thomas 1978, Kurtz 1981, Wolfensberger 1981, Eisenberg 1982, Bogdan 1986, Scheerenberger 1987, Saxton 1988, Hollander 1989, Bogdan *et al.* 1990, Sinason 1992, Shanley & Guest 1995, Cocks 1998). The parents indicated that these values, beliefs and attitudes are still prevalent and often define the behaviour of family, friends and professionals.

The belief that having a child with a disability is ‘unthinkable’ (Ballard 1978) and is one of the ‘most dreaded’ experiences for families (Gill 1991) is so deeply embedded in us that it affects the way in which we respond to and deal with disability, even at a professional level. The parents in this study were angry that their expressions of optimism were interpreted as maladaptive and stated that sensitive, honest communication, which maintains hope, is crucial in promoting strength in them.

Of the theoretical approaches listed in the introduction, chronic sorrow most closely accorded with parents' experiences. Fears and worries related to their current situations and to their children's futures meant that they endured many painful emotions. Grief was confusing, disorderly and unlikely to be neatly resolved. The notion of 'acceptance' was also confusing. They did however, relate to the concept of 'chronic' or 'periodic' sorrow as part of their everyday being.

Whilst sorrow seems self-evident, a great deal of pain derives from societal values and beliefs mirrored in the words and behaviours of friends, family and professionals. In a better world, this pain could be avoided. On the other hand, existential pain and grief (Stephenson & Murphy 1986) cannot be avoided, as it cannot be ameliorated by education and attitudinal change. The parents in this study acknowledged their sorrow and confronted it. Their suffering was a challenging and growing experience, which they believed made them stronger and their grief was placed in the larger context of 'joy' in which they also found meaning. Practitioners could assist parents in a search for meaning rather than ascribing pathological grief responses.

Expressions of joy are given little credence in the professional literature. Voysey (1975) observed that the positive, optimistic words of parents are sometimes dismissed as methodological artefact, statistically insignificant,or explained away by interpretations informed by the researcher's assumptions of pathology. However, whatever the reasons for this scant attention, the parents in this study were very clear – their children with disabilities are a great source of joy.

The parents were also clear that their experience was strengthening. They constructed meaning and developed new perspectives on life as a result of their experiences and challenges. Their perceptions accord with the seminal work of Victor Frankl (1963) who, in writing of 'Man's Search for Meaning', contended that those who have meaning in their lives survive and are healthy.

The notion that denial is a block to a cure of psychiatric illness, coupled with inflexible interpretations of stage models of loss, which hold that the healthy goal of acceptance is unobtainable as long as denial exists, has been reinforced in clinical practice. Emphasis has been placed on the need to acknowledge reality and denial has been seen as maladaptive. Work by people such as Taylor (1989) and Russell (1993) cautions health professionals against asking their clients to be unrealistically realistic, and suggests 'denial buffers the individual against what is sometimes a bleak reality' (Russell 1993, p. 940).

An impetus for the current study was the 'positive contributions' work of Turnbull (Turnbull *et al.* 1988, 1993), which showed people with disabilities within families as a source of joy, learning life's lessons, love, blessing or fulfilment, pride and strength. That work resonates with the words of the parents in this study and summed up by John, who said, 'You've gotta have a good attitude!'. Nolan *et al.* (1996) also write of the 'satisfactions' or 'rewards' and 'gratifications' of the family care of disabled children. The parents spoke of the many joys they derived from their children and from their experiences as their parents.

A mother, Pat Evans (1993) wrote that 'every woman who gives birth to a handicapped child does so in a climate of rejection and fear' (p. 9) and refers to her transformation from fear to love as coming 'out of the rubble of broken dreams'. Like the parents in this study, her own assumptions were challenged, but she still lives in a world that generally devalues people with disabilities. In our model, this incongruity is represented as 'the tensions' and a return to the literature revealed occasional indications of parents grasping this conflicted 'between' state where interdependence of the themes occurs. Mills (1969) identified this interdependence through her practice as a social worker and wrote of families who were '…in many ways [being] on a deeper level because of the suffering and sorrow and the intensity of pleasure when the child takes a step forward' (p. 2). Wikler *et al.* (1983) admitted overlooking strengths in previous research, and quoted a mother saying, 'We hit many peaks and valleys. I would say that there is some sorrow, but our happy moments overshadow the bad times. Our daughter has been a joy and a sorrow' (p. 314). They reported 'a curious combination of sadness and strength …' (p. 314). It is this 'curious combination' which this study conceptualizes as the lens of 'the tensions' where confusions, doubts and ambiguities are located and through which 'joys' and 'sorrows' are given meaning.

Study limitations

Because of the nature of this research, the lack of generalization is recognized. The model presented in Figure 1 is not intended as a theoretical model to be utilized as an interpretation of the states of being of parents of disabled children, but is presented as a visualization of a complex and dynamic interpretation of the stories of six such parents. It is hoped that such a model will enable insight and an expansion of professional thinking and research development.

It is also recognized that the research reports on a brief period in the lives of the families when the children were still young and says nothing about how life might be later.

Whilst the major themes of this research were given voice by all of the parents, there was a sense of a qualitative difference in their experiences. Four of the parents had children whom they had known prior to events that resulted in brain damage, so that these children 'became different'. The other two parents had children with congenital impairments, so their parents came to know them as they 'are'. Because of the small size of this study, the researchers chose to ignore these differences. However, future work would be undertaken with this issues in mind and explicitly addressed.

Despite these acknowledged limitations, this work is being validated by the research of others. Landsman (1999) explored the cultural meaning of being the mother of a disabled child and concluded that, because such experience has caused these mothers to reassess values, realize true priorities, put things in perspective, and be less judgemental, their children are portrayed as 'givers of gifts'. Scorgie and Sobsey's (2000) research explored 'transformational outcomes' and reported significant and positive changes in the lives of parents of children with disabilities. However, it is Larson's (1998) small study, with its focus on the contradictory emotions of grief and joy, hope and fear, which most closely accords with our research in the difficult arena of 'the tensions'. She states:

> The embrace of paradox was the management of the internal tension of opposing forces between loving the child as he or she was and wanting to erase the disability, between dealing with the incurability while pursuing solutions and between maintaining hopefulness for the child's future while being given negative information and battling their own fears (Larson 1998, p. 865).

Conclusion

We have argued that the positive aspects of being a parent of a child with a developmental disability have received scant attention in the professional literature and that the responses of parents with children with disabilities are frequently interpreted within theoretical frameworks of pathology. The cultural meanings we all carry provide assumptions about what life with a child with a disability must be like. These factors result in parents' expressions of joy, hope and optimism being frequently interpreted as 'denial of reality'. We have presented some alternative interpretations and language that afford these parents greater justice. In line with the phenomenological underpinning of this project, parents' expressions of their being-in-the-world with their children must be accepted as their reality, despite the commonly held meanings imposed upon parents of a child with a disability.

Some parents said that encounters with health professionals left no room for hope. They recognized the professionals' commitment to open, factual and honest communication but wanted room for hope. Without hope, there is despair. They believed that their healthy functioning is dependent upon a framework of optimism, and made a plea for support from professionals. This work argues for a professional approach that acknowledges hope, one that should be included in the education of professionals.

Parents require alliances and effective partnerships with professionals (Lehr & Lehr 1990, Hornby 2000) which support their determination. Practitioners must develop a consciousness of the experience of living with a child with a disability as one that is highly individual – there may be pain, suffering and sorrow, but also joy, hope and optimism.

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