Managing Collateral Disability in the Disability Continuum

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ABSTRACT Emotional responses of parents of children with physical disabilities are not clearly addressed in the disability definition and therefore rarely addressed in the course of assessment and management of the disabled patient by the physiotherapists. In the provision of family-centred care for disabled persons, the impact of disablement on every member of the family including carers should be reviewed. This would assist in furthering the bio-psychosocial model of care. This paper briefly outlines the most common emotional responses and collateral disablement experienced by parents of children with disabilities (CWD) and the implications of this to physiotherapy in the family-centred care.

INTRODUCTION

The different responses and coping strategies to the diagnosis of disability within the family has been documented by so many authors (Lawler et al. 1966; Tropauer et al. 1970; Pain 1999; Heaton1999; Sloper 2000; Engler 2005; Waldrop et al. 2005; Anderson et al. 2005). According to Melnyk et al. (2001), the diagnosis of a child's chronic illness is a stressful event for parents. These responses form a series of stages which end in acceptance of the disabled child (McCubbin et al. 1983; Ziolko 1991; Falik 1995).

According to Fortier et al. (1984), the official diagnosis of a handicapped child marks the occurrence of a family crisis. The crisis following the diagnosis of a handicapped child affects the family at many levels. On a behavioural level, the family may need to provide immediate care for the disabled child, arrange transportation to treatment, alter previous methods of scheduling time and meet new financial needs. On the affective level, the family members begin working through feelings of grief, anger, guilt, helplessness and isolation. On a physical or sensory level, somatic symptoms may arise as a result of the crisis experienced. On an interpersonal level the family may have to deal with labeling and stereotyping, a sense of isolation from others, handling "helplessness" and advice from friends, and providing support for other members. On a cognitive level, the family is called upon to get technical information about the disability and to deal with the impact of the diagnosis on established values and expectations. Clubb (1991) reported that some parents would

begin to manifest emotional pain when congenital anomaly such as congenital amputation at birth or obvious deformities like hydrocephalus or microcephallus is observed. In addition to physical pain, Albrecht (1982) also reported limitation of mobility, disorientation, confusion, uncertainty, and disruption of roles and patterns of social interaction.

At best, the onset of disability arouses unresolved ambiguity. The task is to resolve the ambiguity and assign meaning to this very stressful and disruptive series of events. Ambiguity wrecks havoc on the socialization process and on roles because no one knows what to expect. Ambiguity and uncertainty produce stress which in turn inhibits behavioural responses. After onset, the disabled individual and his family and friends need help, but repeated research has shown that it is difficult to get help when the situation is ambiguous (Albrecht 1982; Albrecht and Devlieger1999; Albrecht 2001). Disability affects not only the socialisation of the individual with the injury or disease but all of the persons of importance in his/her life and those with whom he interacts socially. These also experience collateral disability, that is, Disablement that affects parents or carers as a result of the disability (for example, denial of access) of the patient.

In adjusting to the new life resulting from disablement of a member of the family, parents and/ or spouse experiences prejudices, labeling and disablement. This varies between communities, society and environment. The labeling and collateral disablement is dependent upon the meaning given to the cause of disability by

the society. The issue of the meaning of disability has been a central one in the discussions of differences between the natural and social worlds and the generation of appropriate methodologies to understand these worlds (Oliver 1990). According to Oliver (1990, 1993), the social world differs from the natural world in (a least) one fundamental respect; that is , human being give meanings to objects in the social world and subsequently orientate their behaviour towards these objects in terms of the meanings given to them. If disability for example is seen as tragedy, then the disabled people and members of their will be treated as if they are victims of some tragic happening or circumstance. This treatment, Oliver stressed will occur not just in everyday interaction but will also be translated into social policies which will attempt to compensate these victims for the tragedies that have befallen them. Alternatively, it logically follows that if disability is defined as social oppression, then disabled people and members of their families will be seen as the collective victims of an uncaring or unknowing society rather than as individual victims of circumstance. Badley (1993) further stressed that it cannot be denied that many disabilities are socially determined. The meaning attributed to disability also affects parents and carers

Venters (1981) highlighted that one of the most stressful event for families is that of managing a child with chronic or severe illness. The onset of physical disability is accompanied by a complex series of shock to the individual and to everyone around him/her. The impact of disability on the family can have catastrophic consequences for both the individual and the family. McCubbin and Patterson (1982) summarised the hardship of the family life of the disabled child into eight broad categories:

(a) Altered relationships with friends and neighbours due to their reactions to the disabled child along with parental and sibling embarrassment at how the child looks and acts leading to the family's social isolation;

(b) Medical concerns and expenses;

(c) Consultations;

(d) Intra-family stress including over protectiveness, reflection of child and denial of disabilities. Ongoing worry about the child's safety and care, concerns about the extended parenthood, increase in the amount of time focused on the child at the possible expense of other family members, as well as discrepancies between children or as a result of uneven physical, emotional, social and intellectual development. Additional strains emerge from extended family members who may lack the understanding and appreciation of the concerns of parents and siblings of such children;

(e) Specialized care, needs and difficulties related to limited community resources, difficulties in finding the best care and services and the extra costs of specialized care and

(f) Time commitments that disrupt family resources such as extra appointments with medical professionals, consultation associated with special education programmes, and the predictable although disruptive situation of extra demands on family life due to the child's personal and emotional needs in the home setting.

As with all human endeavors, a family's interpretation of the meaning of disability cannot help but reflect to some degree the larger context of social attitudes and historical realities within which that interpretation emerges (Ferguson 2002). In South Africa, the Integrated National Disability Strategy was introduced in 1997 by government to address the issues of disability. Disability has historically been regarded predominantly as a health and welfare issue and responsibility for the 'caring' for the disabled people has thus generally fallen on civil society (Integrated National Disability Strategy (INDS) 1997). According to the INDS (1997), the social attitudes, which resulted from the perception of disability as a health and welfare issue, have invaded all areas of the society. The result is that disabled people and their families have been isolated from their communities and mainstream activities.

Therefore to provide family-centred care for disabled persons, the impact of disablement on every member of the family including care givers shall be reviewed. This would assist in furthering the bio-psychosocial model of care. Emotional responses and collateral disability is rarely addressed in the course of assessment and management of the disabled patient by the physiotherapists. In this paper, a few of the different emotional responses experienced by spouses, parents and other members of the fam-

ily would be reviewed and the implications to physiotherapy would be discussed. It is recognized that the term disabled people and not people with disability is used in conformity with group identity (Oliver 1990), however, for the purpose of this paper children with disabilities (CWD) and handicapped will be used interchangeably.

EMOTIONAL RESPONSES AND ATTITUDES OF PARENTS

Barker et al. (1953) in an earlier study amongst parents identified the following attitudes which were considered distinctly harmful: i) inconsistent behaviour involving careful provision for necessary physical care, together with resentment at the burden this entails. (ii) Outright rejection of the child. (iii) Overprotection, false sympathy, neglect and indulgence, or 'spoiling' of the child.

These attitudes are influenced by emotional pain, which is described by Simon and Smith (1992) as pain which surfaces as children with impairment matured and ventured outside the family. The emotional pain is experienced at various times of the child's development apart from the time of diagnosis (Melnyk et al. 2001) or the "beginning" (Simon and Smith 1992). Melnyk et al. (2001) also reported that as normal healthy toddler and pre-school children struggle with common developmental issues, children with chronic conditions also are challenged to develop autonomy, initiative, and mastery over their environment. Parents desire to promote their child's development, but simultaneously want to protect and assist their child with what they perceive he or she is unable to accomplish. Because they tend to view their child as fragile, vulnerable and different, parents tend to engage in overprotective parenting. Perrin et al. (1989) reported that this style of parenting places children at risk, tagged the "vulnerable child syndrome".

Barker et al. (1953) stressed that culture and socio-economic status was found to influence parents' beliefs. Amongst lower-income groups, parents believe in the inevitability of illness, were suspicious of hospitals and medical care, and looked upon physical impairment as a sign of evil. Parents of higher socio economic status regard physical impairment as unfortunate.

Drotar et al. (1975) found in their study that the most common emotional reaction was sadness. In most cases the anger was directed towards themselves, the baby or outwardly towards hospital staff and other people. Societal demands on all growing children, whether "normal" or disabled are similar. The expectation of parents of children with disabilities through their normal developmental milestones imposes some measure of stress on them. According to Yoos (1987), children with chronic illness need to achieve the same developmental tasks as their healthy peers.

Fear, Worry and Anxiety

Parents of children with a disability described intense anxiety as being a part of their initial reaction to their babies. Many mothers feared for their babies' lives despite most instances of strong reassurance. Parents were also known to report fears that the babies might die. This fear caused a number of parents to feel reluctant to become attached to or interact with the babies. Hesitance regarding this attachment to the babies was seen in all the cases (Drotar et al. 1975). According to Melnyk et al. (2001) infants that are born prematurely, medically fragile, with a genetic defect, or with a chronic condition, faces increased challenges for survival and appropriate development of healthy parent-infant attachments. Parents often have difficulties becoming involved with these infants and developing affinitive feelings towards them because of disappointment, anger, and guilt, grief and/or parental fear that their child may not survive. It was also mentioned that acute and recurrent distress frequently occurs as parents realize that their infant looks and responds differently from other healthy babies or is delayed in development.

Parental responses to the diagnosis of their child's chronic condition commonly include shock, disbelief, denial and anger (Austin 1990; Canam 1993; Eakes 1995; Melnyk et al. 2001). A period of intense emotional upset (including sadness, anger, and anxiety) is usually followed by a period of gradual adaptation, which is marked by a lessening of intense anxiety and emotional reaction. Decreased self-worth and lack of confidence were also common responses (Drotar et al. 1975). Anger can be expressed in various forms such as displacement, passive

aggression and isolation. Parents may avoid other parents with normal children because they feel angry and questions their ability to handle this anger (Fortier and Wanlass 1984). Since many parents have had no previous experience with major physical disabilities, they are unprepared for dealing with them. Moreover, they may have felt, as do so many human beings, that although misfortune may strike others, they themselves are immune. Hence it is not unusual for the parents of a handicapped child to voice the eternal question, "why did this happen to us?"

The Experience of Loss

A common reaction by parents to children with impairment was the sense of losing the imagined or expected child. A notion of flawed beauty was widely reported in connection with feelings of grief, and loss by several parents (Bristor 1984). Loss is part of our everyday life, however, the potential for loss is rarely anticipated in having a child. The birth of a baby is usually thought of with great expectation by the parents and family members. Most family members develop certain expectations, wishes and fantasies during the course of the pregnancy and these dreams embody their hopes for the future. The possibility of this anticipated relationship is abruptly terminated with the birth of a handicapped child (Bristor 1984). According to Bristor (1984), the handicapped infant is a complete distortion of the dreamed-of and planned-for infant.

Parents must grieve the loss of this infant, a process that usually takes many months or longer before they can be fully attached to the living and less than perfect infant. Along with the grieving process is a large component of guilt that can take many forms such as unremitting dedication to the care of the infant to the exclusion of others and must be recognised and worked through. Resentment and anger are signs of grief and probably will be present and directed to those trying to facilitate the grieving. Grief may be time-limited, while mourning may continue for a long time, is periodic and seldom disappears (Olshansky 1962; Mindel and Vernon 1971; Wikler et al. 1981) or postponed (Freud 1924; Kennedy 1970). Most parents achieve partial resolution of this painful emotion (Fortier and Wanlass 1984). Although the experience of loss is most compelling for those directly affected,

family members, personal care givers, and health care professionals also need to cope with, and adjust to, changes. Family members often face altered social roles and responsibilities. They grieve for both their losses and losses of their loved one. Loss challenges all relationships. Some ties are strengthened others may not endure the crisis. Patients and clients need to grieve and adjust to a variety of losses. Drench (2003), indicates that loss, grief, and adjustment are parts of a continuum rather than a linear progression with finite points. Losses associated with chronic, medical conditions have an additional component: a prolonged time frame. According to Simon and Smith (1992), parents found it hard to accept a totally different child than what they had thought they were going to get.

The grief stage is characterised by feelings of guilt and sadness. Parents question "why?" They are angry that they were singled out by fate, and they seek someone to blame. Alternatively they blame themselves, the doctor, their spouse, society and God (Fortier and Wanlass 1984). Parents sometimes reach a point that they are angry with the disabled child for disrupting the family routine and causing great stress within the system (Epperson 1977). Fortier and Wanlass (1984), says that during the grief stage, parents begin to experience self-doubt and humiliation. They need reassurance that (in spite of the child's disability), they are acceptable people. Putting them in contact with others having similarly diagnosed children may help counteract the feelings of being different and isolated from society. This grief reaction is not, as was once believed, a result of the parents' inability to accept the handicapped. On the contrary, according to Cohen (1962), parents intensely wished that there were no handicap, leading them to reject the doctor's diagnosis. In this early period of grief, there may be of a great deal of shopping around for other medical opinions. When the grief behaviour persists beyond the initial two to three months, the grief process has become chronic because the internal process of decathexis of the lost child has not been carried through (Wikler et al. 1981).

Before the parents can master their feelings sufficiently to be able to accept the fact that their child has a handicap, they are placed under considerable stress. Their patterns of adaptation, both individually and within the family may be severely strained. The child's handicap often

triggers personal anxieties and re-opening of old wounds. These anxieties may be reflected in turn in the parental relationships with each other and in their relationships with the other children or with their relatives. In certain instances, the parent view their child's handicap as a punishment for some imagined or real behaviour on his/her own part, which he/she felt was bad (Cohen 1962). According to Bristor (1984), the response to the nature of loss of the desired child was different amongst parents. Mothers and fathers differed in the intensity and expression of their grief.

When there is a handicapped child in the home, the entire manner in which the family has lived may have to be changed. The mother becomes involved not only in arranging for the child to have medical treatment but, also, in instituting a regimen of other forms of therapy such as occupational therapy, physical therapy, and so on; some of which may be carried out at home. Unless she is efficient or an expert, she finds this program of physical care difficult or even overwhelming. Moreover, she realizes that it will have to be continued for a long many years (Cohen 1962). It is only natural that she feels resentful.

Following the experience of grief, there is typically a stage in which adequate coping begins. This stage may determine whether the crisis will resolve in growth or psychopathology. It is at this stage that the individual gives up awful thinking and begins to formulate plans that are congruent with the reality of the situation. At this stage the person is more open to information and better able to accept and evaluate facts and suggestions (Fortier and Wanlass 1984).

Shock

Most parents' initial response to the news of this child anomaly is that of overwhelming shock (Drotar et al.1975; Boushey 2001). In the initial stage, the family, especially the mother may be literally stunned (Bristor 1984; Boushey 2001). Strauss and Munton (1985) further stressed that the birth of the handicapped child terminates the psychological preparation that occurs during pregnancy in anticipation of a "normal infant; the family must cope with the loss of the normal child while integrating the handicapped child into the family.

Guilt, Shame and Anger

Guilt is probably the most commonly invoked category of neurotic responses within the psychodynamic interpretations. Indeed, guilt is seemingly unavoidable, because it can supposedly occur as either a cause or an effect of other emotions. Even parents' involvement in itself has been interpreted as based on an underlying guilt reaction by parents who believe that they are somehow responsible for their child's disability (Solnit et al. 1961; Ferguson 2002). The emphases here are the interplay of parental emotion with the environmental circumstances in which the family found itself. The feeling of guilt, which arises during the grief stage may be intense. Parents feel that they are being punished for some past event. Parents whose children were older when the disability occurred may feel guilty over not recognizing the problem sooner or over not having been more tolerant and understanding towards the child. Guilt can lead to the parents' total dedication to the child. When this occurs, the parent may fail to relate adequately to the other family members or parents may blame each other for the child's disability. Blame can prevent communication and warmth between the parents and the child will sense this (Fortier et al. 1984).

Implications for Physiotherapy

Initial reactions of parents to CWD depend on the answers to the questions posed by them and the supportive attitudes presented by those answering these crucial questions (Strauss et al. 1985). Parents of CWD need early intervention. Experiencing problems and delays in obtaining services adds to parents' grief and erosion of their confidence in the credibility of health-care providers. The fear of the unknown according to Tanner et al. (1998) compounds parental responses to CWD.

The provision of disability specific education or information timeously would assist parents emotionally. According to Pain (1999), personal communication of information most frequently enhances the management of CWD and assist parents to cope emotionally. The information provided at the early stages of care according to Pain (1999) contributes to the process of acceptance and enables them (parents) to manage their children's behavior and provides (par-

ents) the opportunity to plan for the future. It also enables them to access services and benefits that ease their task of raising their children therefore reducing stress and physical duties of caring to a more manageable proportion.

All health care professions including physiotherapists would agree that caring is the heart of their profession (Scotto 2003). Some policy recommends that both patients and carers be involved in discharge plan (the main emphasis for now has been on the patient). The question is should carers' needs be assessed and considered too? (Heaton et al. 1999). The response should be positive for effective and holistic care and holistic.

Involvement of parents in the care plan of CWD through home programmes is one very important management strategy in the care for children with disabilities. It is therefore important that physiotherapists are concerned with the general wellbeing of parents for effective participation and eventual achievement of the set goals. However, the current opinion that parents should be more and more actively involved in the treatment of their children seemed to be based on the positive effect on the children alone (Jansen et al. 2003). Paying a significant attention to parents might also assist amongst others the compliance of parents to instructions of the home programme.

It is also important to note that the relationship between parents and therapists is important in order to achieve treatment goals. A positive relationship might reduce parental stress and assist parents in understanding child's diagnosis and disease progression. According to Jansen et al. (2003), therapists have to make parents feel involved so that compliance to preforming therapies will improve. Improve compliance and competence of provision of care can also be attained by involving them in setting and evaluating goals of the therapy. Active parental participation in family centered-care might also assist in the reduction of negative parental emotions, increase satisfaction and reduce stress. Regular evaluation and assessment of the treatment of the disabled children and their parents might assist in holistic care to parents and children. In addition to parents of CWD, carers and spouses of persons with disabilities should be considered in the care equation in the family- centred care.

Finally, when CWD cannot directly access general facilities, they look up to their parents for assistance. The stress this places upon the parents can be enormous if the cause of the disablement is the society. In some societies, stigma, prejudice, and stereotyping are extended to parents of children with disabilities (Kromberg et al. 1987). Physiotherapists, therefore in the provision of care should attempt to assist parents in alleviating some of these through disability specific education, and provision of resources of various support groups.

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