

**PARENTS' PERCEPTIONS
OF O. T. SERVICES, AS
MEASURED BY THE
MEASURE OF PROCESSES
OF CARE (MPOC) -**

MAUREEN SPITERI

(Dissertation submitted in partial
fulfilment of the requirements for the
Degree of Bachelor of Health Science
(Hons) O.T.)

Introduction

Over the past twenty years, there has been a dramatic change in the nature of service delivery for children with disabilities and the parent-service provider relationship. As opposed to the traditional professional-directed style of child-centred care, a new approach is now opted for, referred to as Family-Centred Care (King et. al, 1999).

Family-Centred care is a philosophy and method of service delivery for children and their parents, which emphasises a partnership between parents and service providers. This philosophy of care is based on a number of important concepts including:

- parents are the ones who know their children best and they want the best for their children;
- all families are different and unique;
- the child's functioning is the result of the supportive family and community context. Hence the child is affected by the stress and coping of other family members (King et. al, 1998; Rosenbaum et al, 1998)

Literature Review

Occupational therapy literature promotes a family-centred care approach, as clients are part of a family structure (Mattingly & Lawlor, 1998). This is especially true in paediatric care, since children do not operate in a vacuum and hence successful intervention requires sensitivity to the perspectives of the parents (Cohn, Miller, & Tickle-Degnen, 2000; Hinojosa & Kramer, 1993). Providing family-centred services requires practitioners to understand what the behaviours, events, persons and institutions mean to those who participate in them (Cohn & Cermak, 1998).

Paediatric literature provides evidence that parents of children with chronic

disabilities such as cerebral palsy not only suffer increased stress and burden as a secondary consequence of their child's condition (Sloper & Turner, 1993), but also have an increased risk of social and mental health problems (King, Rosenbaum & King, 1996). Recent studies show that there is a relationship between aspects of caregiving and parental distress (King et al., 1999; Sloper 1999; Miller et al., 1992).

The powerful influence that parents exert on the developmental gains of their children, has been well-documented (Hinojosa & Anderson, 1991). Hence there is a profound need to involve parents in their child's treatment (McCall & Schneck, 2000). Thus paediatric occupational therapy intervention does not focus solely on the child, but must also target parents. To achieve this, occupational therapists must be cognisant on the parents' expectations, since, if these are not met, the parents' perceptions of occupational therapy services may be affected. In turn the latter may limit the beneficial effect of occupational therapy services for the child (McCall & Schneck, 2000). Similarly Hinojosa and Kramer (1993),

state that it is the family and not the therapist who has the true power, and hence it is only the former who can facilitate or sabotage the intervention process. These authors remark that when the occupational therapist does not consider the important people in the child's environment, the intervention may be inappropriate. They stress the fact that intervention should be conducted in the human context of the child's life; otherwise the treatment is not aimed at the whole person.

There are two possible ways of investigating the nature of the service delivery offered to parents and their children. One way is to investigate the perceptions of the professionals (McBride et al., 1993). However a number of authors agree that the ultimate evaluation of implementation of family-centred care lies in the perception of parents (Carrigan, Rodger & Copley, 2001; King, Rosenbaum & King, 1996; Mahoney, O'Sullivan & Dennebaum, 1990; McBride et al., 1993). Mahoney, O'Sullivan & Dennebaum (1990), report that the only way that services can ascertain that they are truly providing family-centred care is, if the parents

themselves perceive that they are receiving the kinds of services that family-centred care entails. Whilst according to Carrigan, Rodger and Copley (2001), only by obtaining the views of parents can one identify gaps in the existing services. Similarly King, Rosenbaum and King (1996), imply that the receivers of a service are the only true source of information about what type of care is actually received.

Methodology

Although various studies have been carried out to investigate parent's perceptions of family-centered care, and the nature of service delivery (Carrigan, Rodger & Copley, 2001; King et al., 2000; King et al., 1998; King, King & Rosenbaum, 1996; King, Rosenbaum & King, 1996; King, Rosenbaum & King, 1997; Mahoney, O'Sullivan & Dennebaum, 1990; McBride et al., 1993) all of these studies are foreign. Consequently there are no studies that have investigated the local situation. Hence the aim of this study was to examine the parents' perceptions of the extent to which occupational therapy services within a national health service are delivered in a family-centred

manner. This will enable occupational therapists to become more aware of the parents' viewpoints and hence ameliorate service provision. Ultimately this information may lead to the provision of more effective occupational therapy services to serve the children and family members more effectively.

Parents' perceptions were tapped using an already validated questionnaire; the Measure of Processes of Care (MPOC) by King, Rosenbaum and King (1995). It is a 56-item measure of parents' perceptions of service providers' behaviours. It contains five scales: enabling and partnership; providing general information; providing specific information about the child; co-ordinated and comprehensive care for the child and family; and respectful and supportive care. The general format of an item is 'To what extent' does a particular behaviour happen. Parents use a 7-point response option to record their answers. Scales are then calculated by averaging the scores of all items on a scale. No overall MPOC scale is calculated. This likert rating of statements, allows comparisons across studies (McNaughton, 1994).

SCALE NAME	NO OF ITEMS	EXAMPLE OF AN ITEM
		<i>To what extent does the OT that works with your child...</i>
Enabling & Partnership	16provide opportunities for you to make decisions about treatment?
Providing General Information	9	...have information available about your child's disability (e.g., its causes, progress)?
Providing Specific Information	5	...provide you with written information about what your child is doing in therapy?
Co-ordinated & Comprehensive Care	17	...look at the needs of your 'whole' child (e.g., mental, social) instead of just the physical needs?
Respectful & Supportive Care	9	...treat you as an individual rather than as a 'typical parent of a child with a disability'?
Total	56	

Table 3.1.

MPOC – 56 Scales (modified from King, Rosenbaum & King, 1995)

Since the questionnaire (MPOC), was administered in the form of a structured interview, the 7-point response option was printed in a large font so that the participants have a visual image and not simply a mental one. Except for three

interviews that were carried out in English, all the other interviews were done in Maltese.

The MPOC was developed with extensive input from parents and is based on aspects of care that parents view as important. It has sound

psychometric properties (King, Rosenbaum & King, 1995).

The effects of a child with a neurodevelopmental disorder such as cerebral palsy on family life may produce different demands to those of a child with, for example, conduct disorder, as well as different medical and paramedical needs (Sloper & Turner, 1993). Hence for the present study, families of children with cerebral palsy were chosen, as it is assumed that a study of one diagnostic group would reveal consistent issues being confronted by these families.

In this study the target population consisted of the parents of children with Cerebral Palsy that were currently receiving occupational therapy treatment at the Child Development and Assessment Unit in St. Luke's Hospital. Hence the study took place at the Occupational Therapy department at the Child Development and Assessment Unit (CDAU) in Saint Luke's hospital, in Guardamangia, Malta. The researcher carried out the structured interview with 17 parents of children with cerebral palsy. Two parents participated in the

pilot work while 15 participants took part in the main study. Therefore, the two parents that were used for the pilot work were not included in the main study. One of the mothers refused to participate, whilst two other children stopped attending for occupational therapy and hence were not considered as appropriate candidates.

Findings

The findings indicate that parents view Occupational Therapy services as being relatively family-centred. The information from the present study is comparable to information collected in similar studies (King et al., 2000; King et al., 1998; King, King & Rosenbaum, 1996; King, Rosenbaum & King, 1996; King, Rosenbaum & King, 1997).

The parents in the current study indicated that the Occupational Therapy Department was doing well with respect to the interpersonal aspects of service delivery, but that the provision of information was a relatively weak area. As in other studies ((King et al., 2000; King et al., 1998; King, King & Rosenbaum, 1996; King, Rosenbaum & King, 1996; King, Rosenbaum & King,

1997), parents reported that the provision of general information was the aspect of family-centred service that was least well done. Hence it seems that the interpersonal aspects of service delivery are being done well; and it is only the services that are influenced by system level issues, such as Providing General Information, that are not on the same standards.

Conclusion

The Occupational Therapy service under study should strive to improve the provision of information so as to provide services in a truly family-centered manner. A family-centered approach to service delivery leads to parental satisfaction, which is associated with increased adherence to home treatment programs for their children. In turn this is associated with better physical, behavioural and social outcomes for children (Carrigan, Rodger & Copley, 2001; King et. al., 1999; King, Rosenbaum & King, 1996; Rosenbaum et. al., 1998). Research also shows that when parents receive family-centered services, they are less likely to experience feelings of distress and depression (King et. al, 1999). Being

satisfied with services and seeing services as family-centered are not only important outcomes in their own right, but they are associated with a host of other outcomes for both children and parents.

References

- Carrigan, N., Rodger, S., & Copley, J. (2001). Parent satisfaction with a paediatric occupational therapy service: a pilot investigation. *Physical and Occupational Therapy in Pediatrics*, 21(1), 51-76.
- Cohn, E.S., & Cermak, S.A. (1998). Including the family perspective in sensory integration outcomes research. *American Journal of Occupational Therapy*, 52, 540-546.
- Cohn, E.S., Miller, L.J., & Tickle-Degnen, L. (2000). Parental hopes for therapy outcomes; children with sensory modulation disorders. *American Journal of Occupational Therapy*, 54, 36-43.
- Hinojosa, J., & Anderson, J. (1991) Mothers perception of home treatment programs for their pre-school children. *American Journal of Occupational Therapy*, 45, 273-279.
- Hinojosa, J., & Kramer, P. (1993). Influence of the human context on the application of frames of reference. In J. Hinojosa & P. Kramer (eds.), *Frames of reference for pediatric occupational therapy*. (pp. 475-482). Baltimore ; Williams & Wilkins.
- King, G., King, S., & Rosenbaum, P. (1996). Interpersonal aspects of care-giving and client outcomes: A review of the literature. *Ambulatory Child Health*, 2, 151-160.
- King, G., Rosenbaum, P., & King, S. (1997). Evaluating family-centred service using a measure of parents' perceptions. *Child : Care, Health and Development* 23, 47-62.

- King, G., King, S., Rosenbaum, P., & Goffin, R. (1999). Family-centred caregiving and well-being of parents of children with disabilities: linking process with outcome. *Journal of Pediatric Psychology* 24, 41-53.
- King, G., Law, M., King, S., & Rosenbaum, P. (1998). Parents' and service providers' perceptions of the family-centeredness of children's rehabilitation services. *Physical and Occupational Therapy in Pediatrics* 18 (1), 21-40.
- King, S., Kertoy, M., King, G., Rosenbaum, P., Hurley, P., & Law, M. (2000). *Children with disabilities in Ontario: a profile of children's services. Part 2: Perceptions about family-centred service delivery for children with disabilities.* Ontario: Can Child.
- King, S., Rosenbaum, P., & King, G. (1995). *The measure of processes of care - MPOC - a means to assess family-centred behaviours of health care providers.* Users Manual. Ontario: Neurodevelopmental Clinical Research Unit
- King, S., Rosenbaum, P., & King, G. (1996). Parents' perceptions of caregiving: development and validation of a measure of processes. *Developmental Medicine and Child Neurology* 38, 757-772.
- Mahoney G, O'Sullivan P, Dennebaum J. Maternal perceptions of early intervention services: a scale for assessing family-focused intervention. *Top Early Child Spec Educ.* 1990; 10:1-15.
- Mattingly, C.F., & Lawlor, M.C. (1998). Disability experience from a family perspective. In E.N. Maureen, & E.B. Crepeau (Eds.), *Willard & Speckman's occupational therapy* (9th ed.). Philadelphia: Lippincott
- McBride, S.L., Brotherson, M.J., Joanning, H., Whiddon, D., & Demmitt, A. (1993). Implementation of family-centered services: perceptions of families and professionals. *Journal of Early Intervention*, 17(4), 414-430.
- McCall, S., & Schneck, C.M. (2000). Parents' perceptions of occupational therapy services for their children with developmental disabilities. *Developmental Disabilities special interest section quarterly*, 23, 1-4.
- McNaughton, D. (1994). Measuring parent satisfaction with early childhood intervention programs: current practice problems, and future perspectives. *Topics in Early Childhood Special Education*, 14(1), 26-48.
- Miller AC, Gordon RM, Daniele Rj, Diller L. (1992) Stress, appraisal and coping in mothers of disabled and non disabled children. *Journal of Pediatric Psychology* 17: 587-605
- Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: a conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics*, 18(1), 1-20
- Slopper, P., & Turner, S. (1993) Risk and resilience factors in the adaptation of parents of children with sever physical disability. *Journal of Child Psychology and Psychiatry* 34: 167-88
- Sloper, P. (1999). Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, Health and Development*, 25, 85-99.