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Family Intervention in Mental Retardation - An Overview

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Abstract

Home-based family care approach in mental retardation (MR) has gained world-wide recognition and research attention especially in the last 2 decades. There are clear advantages to the individual with MR as well as to society in promoting family based care. However, there is a need to work with families to ensure optimum care as well as successful family adaptation. Approaches to such family interventions include parent education and training, parent counseling, family adaptation and interactive/transactional models. There have been some recent attempts in India to develop family-based interventions. There is a need to devise and evaluate comprehensive care models in MR involving the family members.

Key words -
Mental retardation,
Family based interventions,
Family adaptation,
Indian Studies

The response of the society to their handicapped members, especially those with mental retardation (MR) has varied a great deal over human history [1]. In the recent times, there has been a movement away from Institutional care and towards family-based care of individuals with MR all over the world [2]. In India, overwhelming majority of persons with MR have traditionally been cared for in their families, only a small proportion are being looked after in the Institutions. Of the estimated 2.5 to 3 million persons with severe MR alone (given a prevalence of 3-4/ 1000 general population) less than 10,000 are being cared for in residential institutions [3]. A recent document of Government of India, the National Policy on Mental Handicap [3] has rightly focussed attention on home-based care with parents as partners in care.

This home-based family care approach has received considerable amount of research attention from the professionals dealing with MR in the last 2 decades. This paper addresses several issues concerning the family based interventions in MR.

Rational for Family Intervention

One could cite many reasons arguing for family based intervention (reviewed by Yule [4] and Cunningham [5]) of which the following ones stand out -

(a)**Family consequences:**

The recent research evidence from western countries [6], [7], [8], [9] as well as from India [10], [11], [12] have evaluated the types and degree of stress faced by the families in caring for their handicapped member. By and large, the consensus has been that stress experienced by the family as a whole, and by individual members, especially mother, has been found to be considerable. The experienced stress has been found to be related to certain socio-demographic (social class), child (degree of physical impairment, age, behavior problems and to a lesser extent severity of MR) and family variables (stage of family life-cycle) [9]. The nature of stress has been seen to span over several aspects of family life such as daily care burden, family life such as daily care burden, emotional distress, interpersonal difficulties, financial problems, and adverse social consequences [8], [9], [11], [12], [13].

In view of this, it is reasonable to suppose that one has to devise methods of intervention which address the issue of stress in the family - methods of intervention geared towards reduction/elimination of stress/burden and improvement of family adaptation/coping.

(b)**Advantages to the individual:**

Research evidence has clearly and consistently demonstrated the superiority of home-based care over Institutional Care (reviewed by Cunningham [14]). Further, children with handicaps growing up in better homes have been shown to develop better than others with similar handicaps in 'problem' families [15]. In a classic review, Sameroff and Chandler [15] proposed a model of 'continuum of care-taking casualty' to encompass a host of adverse psycho-social influences on the development of at-risk children. They have martialled compelling evidence suggesting that the environment appears to have the potential of minimising or maximising early developmental difficulties of 'at risk' children.

(c)**Economic/logistic advantages:**

With the existing paucity of trained man-power in the care of persons with MR the increasing realisation that parents can effectively function as resources in the care [5] has raised the hopes for a better and cost-effective care delivery system.

Approaches to family intervention

From a historical perspective, evolution of family intervention models can be traced to 3 developments in this century. Firstly, the child guidance movement [16] in the early decades focused on the role of parents and upbringing in child mental health and optimum psychosocial development and stressed the need for intervening with parents. Eventually, this was found to be true for children with handicaps or those at risk for development disability [15]. Secondly, the behavioral movement in psychiatry made rapid strides in the application of behavior modification techniques in training individuals with MR Beginning with the demonstration of efficacy of behavioral methods for training MR children, the behavior therapists moved on to the training the parents themselves as behavior modifiers for their handicapped children [17], [18], [19], [20], [21]. Thirdly, and more recently research has focussed more and more on the issue of 'family ecology' in terms of studying parental reactions, attitudes stress, coping, resources and adaptation [8], [9], [13], [22], [23], [24], [25], [26]. This approach has emerged as a quite fruitful area of research because it enables the total understanding of MR from family - ecological perspective. Even though the initial work in this area was to study the parents in terms of 'abnormal' reactions from a pathology perspective, the current trend is to view the families from a

'normality' perspective and study the family adaptation in terms of stress and its mediators/modifiers [8], [9], [26].

These trends culminated in a host of early intervention projects starting off with head-start programmes in the U.S. Many of these projects were home-based and/or involved families in intervention [27].

In terms of what intervention is actually carried out with parents/families, one could delineate the following approaches.

(a) Parent education/information.

(b) Parent training, using different theoretical models (such as behavioral and cognitive/developmental).

(c) Parent counselling: In this approach, the focus is not so much on training of parents in specific skills [5], [28].

(d) Family social support, networking and self help groups [29].

e) Transactional interventions: This is a recently emerging approach especially applicable to infants wh [30], [31] or parent related, such as maternal depression and disturbed marital relationship [32] or faulty interactions pattern [33]. There is some empirical evidence to suggest that quality of mother-infant interaction predicts later intellectual functioning [34]. The interventions based on these interactional/transactional models endeavour to optimise parent-infant interactions to be mutually enjoyable and rewarding [33], [35]. Techniques employed under these models include

(i) improving parents observational skills and sensitivity to infants communicative signals [35],

(ii) altering parental responsiveness in a manner which fosters development such as response contingent stimulation [33],

(iii) better handling of infants for physical needs such as postures, feeding practices [30],

(iv) offering sensory stimulation in the context of parent-infant interaction such as stroking, body contact and talking to [30],

(v) using mother-infant games to optimise interactions [36], [37].

Models in India

Initial work in India with regards the role of families in MR addressed themselves to the study of parents such as parental needs [38], Perceptions [39], attitudes [40], and impact [10]. More recently however, a small but significant body of work has emerged reporting on different forms of family intervention [21], [41], [42], [43], [44], [45], [46], [47]. Approaches adapted for these parental/family involvement has varied. Singh [41] and Manju Mehta [42] have exclusively employed behavior modification models, whereas Girimaji et al [45] and Peshwawaria et al [47] have reported on counselling models. Intervention package reported by Varma and Seshadri [46] was more comprehensive, incorporating several models. A new innovative model reported by Narayana et al [44], the brief in-patient family intervention is based on family adaptation, transactional, as well as behavioral models. In all these interventions, though the model description and methods of evaluation have been described to a greater or lesser extent, they limit their reports to 6 months or less.

An UNICEF sponsored on-going project of early intervention modelled along Portage Project at Niloufer Hospital Hyderabad, deserves special mention. Significantly, this is the first large scale early intervention project with high-risk infants with a long-term followup in India. Intervention was carried

out by trained para professionals who periodically made home visits. Preliminary results of this project appear very encouraging [48].

Brief in-patient family intervention model

This model for families with a retarded child was developed at NIMHANS as a innovative approach in 1985 and has been functioning since then. The model was evolved primarily to meet the needs of a sub-group of families who needed intensive intervention for reasons such as presence of high degree of stress and/or poor coping skills in the family consequent to a child with severe MR, often accompanied by other disorders/disabilities. The overall objectives of this intervention are two fold:
(i) to ensure successful family adaptation and
(ii) to ensure optimal care for the child within the family.

The interventions are eccelectic, drawing upon several conceptual models, viz., family adaptation, transactional perspective, physical care, and behavior modification. Thus, the model attempts to offer comprehensive care. The interventions are tailored to suit the needs of individual child and family. The components of this individualised management plan include
(a) medical measures
(b) family orientation and priming
(c) general parenting measures and
(d) parent training.

Preliminary report of this comprehensive model is encouraging [44]. Currently, it is undergoing evaluation in a long-term, prospective, comparative study (funded by Indian Council of Medical Research).

Issues for future research

Given this state of affairs, the following issues can be considered for further research in area of family intervention in MR.

1. More intensive and comprehensive study of child, family, and environmental variables to understand their effect on family's adaptation, successful or otherwise, in a given socio-environmental/cultural setting.
2. Impact of family adaptation on the child's development and well-being.
3. Devising cost-effective models of family intervention which take these factors into account and evaluating them through long-term prospective studies.

Conclusion

Family-based interventions in MR are gaining greater recognition and application all over the world. There has been a clear trend away from a narrow focus on parent training towards more broad-based comprehensive approaches. Recent advances in transactional or relationship focussed interventions

offer exciting new avenues for early intervention. In the Indian context, there is a need to develop and evaluate comprehensive models of family - based interventions.

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48.*Based on a video report of the project provided by Dr. Usha Nayak, Niloufer Hospital, Hyderabad*