PAPERS AND SHORT REPORTS

Impact of a handicapped child on mental health of parents

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Abstract

In a cross sectional study the mental health of parents of physically and mentally handicapped preschool children was compared with that of parents of healthy preschool children. The social networks of the parents with handicapped children were also studied to determine factors that might influence psychiatric morbidity.

The mothers of the handicapped children showed significantly more psychiatric morbidity than the control mothers, but the fathers did not show the same deleterious effect on mental health.

Introduction

The carers of the chronically disabled are exposed to many burdens and disappointments that limit their quality of life.[1] Parental self esteem is closely entwined with a child's development and accomplishments, so the care of one's own handicapped child might be expected to be especially burdensome. Solnit and Stark characterised the response of parents to the birth of their defective child as mourning the death of their fantasised perfect child,[2] and others have highlighted the chronic sorrow of such families.[3]

Many reports have appeared in journals on general practice, paediatrics, psychiatry, and education and have been well reviewed.[4-7] Unfortunately, many of these reports have been marred by a lack of control groups, poorly specified study populations, especially with respect to the child's handicap, pervasive omission of fathers, and the use of assessment techniques that have not been validated. Earlier research focused on the differences between families whose handicapped child was cared for in an institution and those whose child was not.[8,9] Recently, with the increase in community care, questions have surfaced about the impact of a handicapped child on family function.[10]

We have studied the influence of seriously handicapped children of preschool age on the mental health and social networks of their parents.

Subjects and methods

The study was conducted in Dunedin, a university city in the South Island of New Zealand with a population of 105 000. Of the city's 1500 babies born each year, five may be expected to be severely intellectually handicapped,[11] one or two to have spina bifida,[12] and probably a further three to be afflicted with cerebral palsy.[13] During the study no preschool child was permanently cared for in an institution, and only one family chose not to use a specialised preschool education facility for handicapped children.

SUBJECTS

Three city facilities provided education for handicapped preschool children, and each gave permission for us to contact the parents of children who attended. All the children of subject parents had major physical or mental handicap, or both. Consequently they were unable to comply with the general educational policy of handicapped children attending normal preschool facilities whenever possible.

Demographic family data were gathered. Parents' employment state was assessed on the basis of weekly hours of paid employment. Social class was assessed from the husband's occupation according to the usual New Zealand classification.[14] No wives were employed for more hours than their husbands. Single mothers were classified separately.

All subjects completed Goldberg's 60 item general health questionnaire, a self rated screening instrument designed to detect psychiatric disorder in a community setting.[15,16] Social network profiles of these parents were studied during a home visit with the interview schedule for social interaction of Henderson *et al.*[17-19] This 52 item structured interview assesses aspects of the interviewee's relationships, both intimate (attachments) and more general (social integration).

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CONTROLS

New Zealand has four preschool systems for normal children. Kindergartens are state run by the department of education and have limited parental participation. Play centres are run by voluntary organisations, who train their own staff and rely heavily on help from mothers. Maximum attendance by children at these two types of centre is four half days a week. Private day care centres provide full time education and are usually selected by parents to suit their hours of employment. The fourth system, Maori language nests (Te Kohanga Reo), was not represented in Dunedin during the study.

Each organisation nominated two representative preschools, which made available their register of parents of currently enrolled children. None of these control parents used for comparison had a handicapped child. Questionnaires were distributed personally to parents when they collected children and were returned by mail. These control parents were asked to provide demographic data and complete the general health questionnaire 60. They were not interviewed about their social networks, as the main focus of our investigation was to screen for minor psychiatric morbidity in the two populations. Parents who had not returned questionnaires within two weeks were reminded by telephone.

STATISTICAL ANALYSIS

As the results of the general health questionnaire are not distributed normally, non-parametric statistical tests were used when analysing scores and calculating confidence intervals.[20-22] The relation between maternal scores for the general health questionnaire, parental group (subject or control), social class, and employment state were examined by fitting a hierarchal log linear model to the data.[23] For this procedure data on each mother were split into one of two categories: subject or control, high or low social class, employed or not employed, and high or low general health questionnaire score. The best log linear model was then obtained by backward elimination of terms from the saturated model.

Results

All mothers and 82% of the fathers in the group of subjects participated, and 93% of the mothers and 82% of the fathers in the control group participated. Table I shows the demographic parental data.

The children of the subjects had a wide range of diagnoses typical of those seen in most large paediatric clinics. One family had two children receiving special education. The main diagnoses were: moderate developmental delay and intellectual handicap of uncertain aetiology (14 children); cerebral palsy, usually with intellectual handicap (13); severe intellectual handicap of uncertain aetiology (five); congenital abnormality, such as dislocated hips requiring prolonged postoperative treatment in plaster, severe inoperable heart disorder, and cleft palate with associated problems (five); chromosomal abnormality (four, of which two were Down's syndrome); and a series of single children with a more uncommon diagnosis—for example, Prader-Willi syndrome, tuberous sclerosis, severe asthma, brain damage resulting from physical abuse, muscular dystrophy, spina bifida, and epilepsy.

SCORES ON GENERAL HEALTH QUESTIONNAIRE

The degree of morbidity as ascertained by the general health questionnaire was significantly greater in the 54 mothers of handicapped children than in the 184 mothers in the control group ($p<0{\cdot}002$, Mann-Whitney U test) (table I). Thirty five per cent of subject mothers scored above the usual cut off point of 12 or more compared with 21% of the control mothers. As psychiatric morbidity is known to be influenced by social class and employment state, this difference in score for the general health questionnaire could have been accounted for by demographic differences between the two groups. Such differences were therefore examined in more detail.

There were no significant differences between the two groups of parents in age or number of children (Mann-Whitney U test), or in marital state (χ^2 test$=2{\cdot}0$, 1 df, NS). In all six subject and 17 control single parent families the mother was the custodial parent. The social class of women in the subject group was lower than that of women in the control group ($p=0{\cdot}003$, Mann-Whitney U test). There was no significant difference in the proportion of mothers with paid employment between the subject and control groups ($\chi^2=0{\cdot}2$, 1 df, NS). In the log linear analysis the only significant interactions found were between parent group and the score for the general health questionnaire (partial $\chi^2=4{\cdot}8$, 1 df, $p<0{\cdot}05$) and between parent group and social class (partial $\chi^2=15{\cdot}1$, 1 df, $p<0{\cdot}001$). Hence when controlling for social class and employment state significantly more mothers of handicapped children had high scores for the general health questionnaire than control mothers (table I).

The scores for the general health questionnaire for 43 fathers in the subject group did not differ significantly from those for the control group of 132 fathers (table I). Twenty one per cent of subject fathers and 16% of control fathers scored above the cut off point and probably would have received a psychiatric diagnosis if examined.

The items on the general health questionnaire most often scored by parents in the subject group (54 F, 43 M) were: not feeling full of energy (19 F, nine M), getting edgy and bad tempered (17 F, 10 M), getting up feeling unrefreshed by sleep (13 F, nine M), feeling in need of a good tonic (13 F, nine M), and feeling constantly under strain (13 F, nine M).

The scores for the general health questionnaire for the six single mothers in the subject group were mean (SD) 0·833 (1·6), median 0, and range 0-4. Such scores were no higher than the scores for the married mothers in the same group; in fact they were lower ($p=0{\cdot}02$, Mann-Whitney U test).

SOCIAL NETWORKS AND PSYCHIATRIC MORBIDITY

To assess the relation between social support and psychiatric symptoms the scores on the general health questionnaire of the mothers and fathers in the subject group were tested separately for associations with the seven scores for the interview schedule for social interaction with Spearman's rank correlation (table II).

For the mothers there was no significant correlation between the social network variables measured and morbidity as determined by the general health questionnaire. Those subject fathers whose score for the general health questionnaire was high, however, were significantly more likely to rate their attachments (intimate or marital relationships) as unavailable and inadequate; they also reported experiencing their wider social integration as being inadequate.

Discussion

The mothers of handicapped preschool children showed significantly more psychiatric symptoms than a comparable group of

TABLE I—*Data from demographic survey and general health questionnaire for subjects and controls*

	Subjects		Controls	
	Mothers	Fathers	Mothers	Fathers
No sent questionnaire	54	43	184	132
Response rate (%)	100	93	82	82
Mean (SD) age (years)	29·6 (5·2)	33·9 (7·1)	30·7 (4·1)	34·4 (5·6)
Mean (SD) social class*	3·6 (1·3)	3·5 (1·2)	2·6 (1·2)	2·5 (1·6)
% Married	83	95	91	100
% Employed	24	100	31	100
Mean (SD) No of children	2·3 (1·2)		2·5 (1·0)	
Score for general health questionnaire:				
Mean (SD)	10·19 (11·26)	6·93 (11·98)	6·03 (9·34)	4·27 (6·65)
Median (range)	5 (0-48)	2 (0-56)	2 (0-50)	1 (0-27)
95% Confidence interval	2 to 10	0 to 4	1 to 3	0 to 3
% Likely to receive a psychiatric diagnosis if examined	35·2	20·4	21·2	15·9

*Assessed from usual New Zealand classification.[14]

TABLE II—*Spearman's rank order correlations between scores for general health questionnaire and social network indices for subjects*

	Mothers		Fathers	
	r	Significance*	r	Significance*
Availability of attachment	0·01	NS	−0·21	NS
Adequacy of attachment	−0·09	NS	−0·45	p=0·001
% Of adequate attachments	−0·08	NS	−0·44	p=0·002
Satisfaction with missing attachments	0·00	NS	0·08	NS
Availability of social integration	0·27	NS	−0·15	NS
Adequacy of social integration	−0·12	NS	−0·39	p=0·005
Recent rows and unpleasantness	0·38	p=0·004	0·20	NS

*Significant correlation was taken as $p=0{\cdot}05/7=0{\cdot}007$ to adjust for multiple testing.

mothers of healthy preschool children, even after controlling for social class and employment.

The parents in the subject group were typical of families with a severely handicapped child. All families except one, known to the hospital service, were located through the preschool facilities, and all parents except two fathers participated. Because mothers of small children, whether the children are handicapped[24 25] or not, have an increased risk of psychiatric morbidity,[26-31] the choice of an appropriate control group was essential. Nationally, 88% of New Zealand children of European origin attend a preschool.[32] The proportion in Dunedin is higher, as shown by the 93% attendance in a large prospective child development study.[33]

As expected, our control parents enjoyed higher average socioeconomic state than parents in the subject group, and more control mothers, though not significantly more, were employed than mothers in the subject group. Hence the log linear analysis of the interaction between social class, employment, and psychiatric symptomatology was important. A truly random sample of control parents could not be generated, as the different preschool organisations do not hold a single centralised roll. As the parents with healthy children were similar to the parents of handicapped children on all demographic variables other than socioeconomic state and an excellent response rate was obtained, however, the final group was a suitable sample for comparison.

Unlike the mothers of handicapped children the fathers did not show more psychiatric symptoms on the general health questionnaire than the control fathers. This questionnaire detects symptoms of malaise, fatigue, anxiety, and depression—so called minor psychiatric morbidity—and does not identify the much rarer psychotic, substance abuse, and personality disorders. The burden of child care falls squarely on the shoulders of the major carer, who is more likely to display psychiatric symptoms. Most researchers suggest that social factors determine the observed increase of minor psychiatric morbidity in women caring for children.[27-31] This study shows that additional care tasks widen further the difference between the sexes in psychiatric morbidity.

The social network variables describe various aspects of a person's social environment. By correlating the indices from the interview schedule for social interaction and the scores for the general health questionnaire it was possible to determine whether highly symptomatic parents differed in their perceptions of their social relationships from non-symptomatic parents. No difference emerged for mothers. Women with high scores for the general health questionnaire were no more likely to rate either their intimate or their more general social relationships as unavailable or inadequate, though they were more likely to have recently experienced rows or unpleasantness with others. Whatever the mechanisms by which mothers of handicapped small children become stressed, the burden of care does not seem to create measurable changes in their social interactions. In contrast, the one fifth of fathers with high scores for the general health questionnaire more often described their relationships as impaired. They tended to see both intimate and more general social contacts as inadequate.

Many women are able to engross themselves in the care of their handicapped child, and their involvement in the task of caring for the child probably makes them relatively unavailable to their husbands. Many mothers spontaneously commented that they could not make visits outside their home easily either with or without their handicapped child and felt conflicts about asking others to babysit. Such experiences may impair their husband's ability to participate fully in the wider community.

Causality cannot be established in a cross sectional study, but these findings add to the accumulating evidence that suggests that caring for a handicapped member of the family is stressful and contributes to psychiatric morbidity. Dupont, in a recent discussion on the sociopsychiatric impact of the young severely mentally retarded on families, stated that "in most cases mothers carried the burden of child care and housework with little support."[34]

Our study shows that caring for a handicapped child has a great impact on the mental health of mothers. The effect on paternal mental health is less and may occur indirectly by affecting their wives' emotional availability to them. Most writers have found considerable marital conflict present in families with handicapped children, often resulting in an increased rate of divorce.[4 6 34 35] Factors that affect the mental health of parents with such children include characteristics of the child such as temperament, age, and gender[36-38] and certainly the financial resources available to cope with the increased cost to the family.[39 40]

This study belongs to a developing topic of investigation that seeks to describe the ways and the extent to which the care of a chronically ill member alters a family's function.[10] When the impact of the task of caring is understood the community will be better able to protect its most valuable resource of caring, the family.

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