Research Article

The Burden of Caring for Children with Emotional or Conduct Disorders

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Introduction. There is a paucity of evidence from epidemiological studies on the burden of children's emotional and conduct disorders on their parents. The main purpose of this study is to describe the problems experienced by parents of children with conduct and emotional disorders using data from a large national study on the mental health of children and young people in Great Britain. Materials and Methods. The Development and Well-Being Assessment and sections of the Child and Adolescent Burden Assessment were included in a nationally representative survey of the mental health of 10,438 children, aged 5–15, in Great Britain. Results and Discussion. Approximately half the parents of children with conduct disorder reported that they felt restricted in doing things socially with or without their children, embarrassed about their child's problems, and that these also made the relationship with their partner more strained. Conclusions. There is a growing need for research on the consequences of children mental disorders on families to increase the awareness of frontline workers on the burden to parents. Because parents feel embarrassed and stigmatized, they may hide their own feelings which may further exacerbate the situation.

1. Introduction

The terms, caregiver stress, caregiver strain, and caregiver burden have all been used to describe the needs, responsibilities, difficulties, and negative psychological effects of caring for a dependent relative [1, 2].

According to Brannan and Heflinger [3], caregiver strain has two dimensions: objective caregiver strain comprises the observable negative occurrences and constraints resulting directly from the child’s problems (e.g., difficulties with neighbours and police, disrupted family relationships, financial strain, and interruption at work) and subjective caregiver strain which constitutes the caregiver’s feelings towards those occurrences (e.g., stigma, guilt, anger, sadness, embarrassment, and worry). In brief, objective burden can be regarded as the observable disruption of aspects of the caregiver’s life, whereas subjective burden is the extent to which the caregiver perceives care responsibilities to be stressful [4–6].

Parents and caregivers of children with emotional and behavioural disorders often experience significant burden associated with care of the child [2, 3, 6, 7]. These comprise financial burden, conflicts between family members, high irritability and overprotection in families, effect on family social life, interruption at work, fatigue, sadness and limitations on time, personal freedom, and privacy [2, 4, 8, 9].

Commonly, caregiver strain also has implications for children's entry into mental health services, engagement with practitioners, concordance with recommended interventions, and service use patterns when having treatment.

As children with emotional or behavioural problems require more supervision and attention than a normal child would, parents tend to avoid public places such as cinemas, restaurant, shops, and public transport. Parents can also feel
embarrassed and shamed by their child’s behaviour when they visit relatives or friends. This results in reduced social contact. Adverse family interactions (parent-child, marital, and siblings) are also often linked to the child’s behaviour [7].

In contrast to parents, other relatives caring for a child with emotional and behavioural disorder may not experience the same feeling of guilt or burden as parents [2]. However, kinship caregivers (e.g., grandparents, aunts, and siblings) have been reported to experience caregiver strain at levels similar to parents [4].

Using data from a large national study on the mental health of children and young people in Great Britain, the purpose of this study is to describe the problems experienced by parents of children with conduct and emotional disorders. These problems cover relationships with other family members, their social life, and expressions of stigma (embarrassment) and discrimination (avoidance). We examine the extent to which the distribution of the 10 items used to illustrate caregiver stress or burden are associated with biographic and sociodemographic characteristics of the child and parent. Among those parents who do express problems in caring for their children with emotional or conduct disorders, we examine their own contact with services in order to alleviate their stress.

2. Methods and Materials

2.1. Sample Design. The parents of each child under 16 living in the United Kingdom are entitled to receive child benefits unless the child is under the care of social services. The centralised computerized records from the Child Benefit Register (CBR) were used as a sampling frame to select children aged five to 15 throughout England, Wales, and Scotland. Using centralised records as a sampling frame was preferred for carrying out a postal sift of over 100,000 addresses and for sampling through school as it provides better coverage and is cost effective.

A total of 14,250 opt-out letters were dispatched by the Child Benefit Centre—30 letters for each of the 475 postal sectors. Nine hundred and thirty one of the sampled addresses (6.5%) opted out, and a further 790 addresses (5.5%) were found to be ineligible—the family had moved, and the child was deceased or had been placed in foster care. Among the cooperating families, almost all the parents and most of the children took part. Four out of five teachers returned their questionnaires, based on an initial mailout and one reminder letter.

Therefore, just over 12,500 addresses were allocated to around 300 interviewers. Information was collected on 83% of the 12,529 children eligible for interview from up to three sources resulting in at least some data for 10,438 children.

2.2. Measurement of Childhood Mental Disorders. The survey instrument used to produce the prevalence of clinically recognisable mental disorders among children was the Development and Well-Being Assessment (DAWBA). It was designed for use in the first national survey of child mental health in Great Britain. The DAWBA was constructed in order to combine some of the best features of structured and semistructured measures. This new structured interview was supplemented with open-ended questions. When definite symptoms were identified by the structured questions, interviewers used open-ended questions and supplementary prompts to get parents and young people aged 11 or over to describe the problems in their own words. An abbreviated form was mailed to a teacher nominated by the family as knowing the child well.

A case vignette approach was used for analysing the survey data, that is, using clinician ratings based on a review of all the information for each child—potentially from parent, child, and teacher. The case vignette approach was extensively tested among children who had been and those who had not been in contact with child mental health services in the prepilot and pilot phases of the survey [10]. Diagnoses were subsequently generated based on the ICD-10 research diagnostic criteria [11] using the information from all available informants.

In validation studies, the DAWBA provided excellent discrimination between children known to have mental disorders and those with no mental disorder [10]. There were high levels of agreement between diagnoses arising from the DAWBA data and from the case notes of children in contact with child psychiatrists. (Kendall’s tau $b = 0.47–0.70$).

2.3. Measurement of Parental Burden or Stigma. Ten questions were chosen from the Child and Adolescent Burden Assessment [12] (later renamed the Child and Adolescent Impact Assessment) to represent both objective and subjective caregiver stress [13]. These questions were only asked of parents who indicated that they had significant problems with their children.

(i) Child’s problems have kept parent from doing things socially with child—to a great extent, to some extent, or not at all.

(ii) Child’s problems disrupted parent’s social and leisure activities—to a great extent, to some extent, or not at all.

(iii) Child’s difficulties have caused embarrassment—yes, no.

(iv) Child’s problems made relationship with partner—stronger, more strained, or made no difference.

(v) Child’s problems made partner’s relationship with other children—stronger, more difficult, or made no difference.

(vi) Parent has felt disapproved of or avoided because of child’s difficulties—yes, no.

(vii) Child’s problems made relationship with other children—stronger, more difficult, or made no difference.

(viii) Child’s problem put a strain on a previous relationship and was part of the reason the relationship broke up—to a great extent, to some extent, or not at all.
Lay interviewers (approximately 300) regularly involved in

3. Data Collection Procedure

Lay interviewers (approximately 300) regularly involved in
the British Office for National Statistics surveys were used
to collect the survey data. Special attempts were made
to trace families whose addresses or names had changed
because of various circumstances. Because of the need
to collect accurate quantitative and qualitative data within
the DAWBA, interviewer training emphasized the need to obtain
respondents’ descriptions of any problems and concerns in
their own words, facilitating this with open-ended prompts
and recording the answers verbatim.

Interviewers completed the face-to-face interview with
the parent or main caregiver first—about 95% were mothers,
and permission was subsequently sought to ask questions
of the sampled child. Young people aged 11 or over
had a private face-to-face interview and also completed a
computed-assisted self-completion interview (CASI) directly
on a laptop computer for more sensitive questions about
violent behaviour, smoking, alcohol, and drug experiences.

At the end of the interview, parents or carers were asked to
nominate a teacher who knew the child well; the SDQ was
subsequently mailed to this teacher. A reminder letter was
sent to teachers who did not respond.

4. Statistical Analyses

Our approach to the analysis of the survey data is initially
to describe and compare by means of crosstabulations the
burden and stigma experienced by parents according to the
diagnosis of mental order—emotional disorders and conduct
disorders. Because children can have co-occurring disorders,
three categories were produced: emotional disorders, con-
duct disorders, and both emotional and conduct disorders.
Significant differences are commented upon. Multiple linear
regression analysis is used to examine the extent to which
characteristics of the child (age and sex) and household
characteristics (tenure) increase the likelihood of parents
giving affirmative responses when presented with each burden or stigma item. We then return to crosstabulations to
describe and compare parental reports of psychological
distress associated with their child's mental disorder and
what they did about such feelings. Finally, we use Chi-
squared analysis to examine the relationship between the
severity of caregiver burden and the likelihood of parents
taking their children to see appropriate mental health
services.

To improve the representativeness of the survey, a
weighting procedure was applied to the data. The data were
weighted (a) to take account of differential sampling of postal
sectors by country within Great Britain, (b) to match the
age/sex distribution of 5–15 year olds in the population at
the time of the survey, and (c) to compensate for response
variability by metropolitan and nonmetropolitan regions,
that is, poorer response in inner cities.

5. Results

5.1. Parental Burden in Relation to Type of Disorder. There
was a trend for the parents of children with emotional
disorder to report the lowest level of burden on all items, with
the parents of children with both conduct and emotional
disorders reporting the highest level of burden. The parents
of children with conduct disorder only reported levels of
burden that were either intermediate or similar to the parents
with co-occurring emotional and conduct disorder (Table 1).

5.2. Characteristics of the Child Associated with Caregiver
Burden. Parents of girls with conduct disorder compared
with parents of boys with conduct disorder were more likely
to say that they experienced embarrassment caused by their
child’s behavioural difficulties (OR = 1.65, 1.01–2.68, P <
.05). The converse relationship was found for parents of
children with emotional disorders, and the odds of parents
duaghters with emotional problems feeling embarrassed
were halft that of parents of boys (OR = 0.48, 0.26–0.88,
P < .01). Parents of children and young people classified as
having both emotional and conduct disorders did not appear
to express different levels of embarrassment by sex nor did
the sex of the child seem to be associated with any other
expression of caregiver’s burden.

On the other hand, the age of the child was related to two
elements of caregiver stress, but this only occurred among
children with emotional disorders.
### Table 1: Burden and stigma experienced by parents of children with conduct disorder and/or emotional disorders.

| Burden and stigma items                                                                 | CD only % | ED only % | CD and ED % |
|---------------------------------------------------------------------------------------|-----------|-----------|-------------|
| Child’s problems kept parent from doing things socially with the child                 |           |           |             |
| To a great extent                                                                     | 20.1      | 8.4       | 22.9        |
| To some extent                                                                        | 32.5      | 23.4      | 32.0        |
| Not at all                                                                             | 47.4      | 68.2      | 45.1        |
| Child’s problems disrupted parent’s social and leisure activities                      |           |           |             |
| To a great extent                                                                     | 15.8      | 10.6      | 24.0        |
| To some extent                                                                        | 34.3      | 28.6      | 36.9        |
| Not at all                                                                             | 49.8      | 60.9      | 39.1        |
| Child’s difficulties have caused embarrassment                                         |           |           |             |
| Yes                                                                                   | 46.2      | 10.6      | 46.3        |
| No                                                                                   | 53.8      | 89.4      | 53.7        |
| Child’s problems made relationship with partner*                                       |           |           |             |
| Stronger                                                                              | 13.9      | 19.2      | 15.2        |
| More strained                                                                         | 45.6      | 19.1      | 60.4        |
| No Difference                                                                         | 40.5      | 61.8      | 24.4        |
| Child’s problems caused difficulties with other family members                          |           |           |             |
| Yes                                                                                   | 35.3      | 14.2      | 34.8        |
| No                                                                                   | 64.7      | 85.8      | 65.2        |
| Child’s problems made partner’s relationship with other children more difficult*       |           |           |             |
| Stronger                                                                              | 3.6       | 16.5      | 6.1         |
| More difficult                                                                       | 37.6      | 18.5      | 45.3        |
| No difference                                                                         | 47.7      | 56.3      | 33.4        |
| No other children                                                                     | 11.1      | 8.8       | 15.2        |
| Parent has felt disapproved of or avoided because of the child’s difficulties          |           |           |             |
| Yes                                                                                   | 33.6      | 16.6      | 44.1        |
| No                                                                                   | 66.4      | 83.4      | 55.9        |
| Child’s problems made relationship with other children                                 |           |           |             |
| Stronger                                                                              | 6.4       | 10.7      | 10.5        |
| More difficult                                                                       | 29.8      | 16.0      | 46.2        |
| No difference                                                                         | 57.1      | 66.3      | 40.9        |
| No other children                                                                     | 6.7       | 7.0       | 2.3         |
| Child’s problem put a strain on a previous relationship and was part of the reason the relationship broke up* |
| To a great extent                                                                     | 10.4      | 5.9       | 17.0        |
| To some extent                                                                        | 15.2      | 5.1       | 12.1        |
| Not at all                                                                             | 63.3      | 79.8      | 64.2        |
| No previous relationship                                                              | 3.4       | 0.0       | 0.0         |
| Problem started since relationship                                                     | 7.7       | 9.2       | 6.6         |
| Child’s problems caused difficulties with parent’s own relationships with friends      |           |           |             |
| Yes                                                                                   | 17.7      | 8.6       | 31.3        |
| No                                                                                   | 82.3      | 91.4      | 68.7        |
| Base                                                                                 | 312       | 306       | 90          |

Parents of younger children with emotional disorders were three times more likely to say that their child’s problems caused difficulties with other family members (OR = 3.05, 1.52–6.12, P < .001). If the children had both conduct and emotional disorders, the parents of the younger children were more prone to report feeling disapproved of or avoided (2.42, 1.02–5.74, P < .05).

5.3 Characteristics of the Family Associated with Caregiver Burden. Socioeconomic status (as measured by housing
Table 2: Parental reports of psychological distress by the type of child’s mental disorder.

| Burden and stigma items          | CD only | ED only | CD and ED |
|----------------------------------|---------|---------|-----------|
| Would you say they have made you worried? |         |         |           |
| To a great extent                | 53.1    | 30.5    | 57.4      |
| To some extent                   | 39.9    | 51.6    | 35.8      |
| Not at all                       | 7.0     | 17.9    | 6.9       |
| Would you say they have made you tired? |         |         |           |
| To a great extent                | 30.5    | 18.4    | 41.1      |
| To some extent                   | 45.9    | 37.6    | 37.5      |
| Not at all                       | 23.6    | 44.0    | 21.4      |
| Would you say they have made you depressed? |         |         |           |
| To a great extent                | 21.0    | 13.6    | 35.6      |
| To some extent                   | 41.5    | 31.9    | 46.7      |
| Not at all                       | 37.5    | 54.5    | 17.7      |
| Would you say they have made you psychologically ill? |         |         |           |
| To a great extent                | 9.9     | 8.0     | 19.6      |
| To some extent                   | 18.2    | 12.3    | 26.3      |
| Not at all                       | 71.9    | 79.8    | 54.1      |
| **Base**                         | 312     | 307     | 90        |

6. Health of Burdened or Stigmatised Parents

When parents of children with conduct disorders were asked how their children’s behavioural problems affected them, the vast majority, nine out of 10, said they were worried about their children, about three quarters said they were tired, and just less that two-thirds said it made them depressed. Just over a quarter said their child’s problems made them physically ill (Table 2). There were similar trends in the pattern of responses to the items on burden, with parents of children with emotional disorders reporting less ill health than the parents of children with comorbid disorders, with the parents of children with conduct disorders being intermediate or similar in the level of ill health reported to parents of children with both emotional and conduct disorders. As Table 2 shows, there were substantial numbers of these parents reporting ill health. Between a quarter (ED only) and a half (ED and CD) actually went to their GP for help for their distress, and about two-thirds of them were prescribed medication. (Table 3) Again the parents of children with comorbid emotional and behavioural disorders reported the highest rates of consulting primary care and prescription medication. The survey did not include questions asking for the name of the medication.
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caregiver and family [4].

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and significantly elevated levels of caregiver strain related to their
child’s disorder [2, 4, 8]. One explanation that has been

8.1. Comparison with Other Studies. The substantial levels
of parental burden resulting from the care of children with
mental disorders were also detected in a US study [1]. Using
the Child and Adolescent Burden Assessment (CABA),
Angold et al. found that a significant proportion of their
study sample had at least one perceived burden [1]. In a
study in China, Liu and colleagues found that most parents
of mentally ill children experienced pressure in their life, and
97.9% of them had increased anxiety [6]. Moreover, over
half of parents in their study indicated that their leisure time
significantly decreased, and over a third of them reported
that they were reluctant to invite friends into their house
since their child had developed their problems. Parental
feelings of burden and stigma seem to be evident across
cultures.

8.2. Why Elevated Rates among Conduct Disorders? Our
finding that children with conduct disorders seem to provoke
the most caregiver burden fits into the well-established view
that parents of children with externalised disorder report
significantly elevated levels of caregiver strain related to their
child’s disorder [2, 4, 8]. One explanation that has been
put forward is that externalizing behaviour is disruptive
and difficult to manage, makes the caregiver role more
challenging, and clearly adds considerable stress on the
caregiver and family [4].

Emotional disorders are less persistent than conduct
disorders and may be less “visible,” which may explain the
lower rates of parental burden among parents of children
with anxiety and depressive disorders. It is also possible
that having a child with an emotional disorder may be (or
perceived to be) more likely to attract sympathy and support,
while parents of children with challenging behaviour may be
more likely to be blamed, to fear being blamed, or to blame
themselves for their children’s difficulties. Self-stigmatisation
among adults with mental illness may have as great a
negative impact on the individual as active discrimination
[14]. However, the current study suggests that there are
socioeconomic influences on the impact of burden among
parents, with emotional disorders leading to greater burden
among families living in more deprived circumstances and
the reverse being true for conduct disorders.

8.3. Caregiver Burden by Biographic and Sociodemographic
Factors. Whereas some previous studies did not find the
child’s gender or age to be predictors of caregiver stress
[6, 8], this study found that more parental embarrassment
resulted from “gender atypical” disorders, that is, girls with
behavioural problems and boys with emotional problems.
This indicates that internalizing and externalizing disorders
should be considered separately in terms of caregiver’s
burden.

8.4. Caregiver Burden and Use of Mental Health Services. The
strong direct relationship between caregiver strain/burden
and the increased use of children’s mental health services has
been found in several studies [15]. Caregiver strain has been
identified by a number of studies as the greatest predictor
of service use [1, 8, 16], and a growing body of evidence
indicates that caregiver strain is associated with increased
child use of mental health service beyond what can be
explained by severity of symptoms [4]. For instance, parental
burden from child psychiatric disorders was a major cause
for mental health service use in rural areas [1]. The presence
of perceived burden was associated with at least a fivefold
increase in the rate of specialised child mental health service
use by children [1]. However, our study found a fivefold
increase in contact with social workers.

8.5. Study Limitations. Although the participation rate of
parents and young people in the survey was high, about
a quarter of sampled households could not be contacted
or refused. Parents who refused to take part or could not

### 7. Use of Services

Feelings or experiences of caregiver stress appeared to
stimulate the parent to do something to reduce the problem
(accessing appropriate child services) as well as seeking help
from their GP to cope with their own difficulties. The data
in Table 4 suggest that the greater the range of caregiver
stress experienced, the greater likelihood the parent sought
out health and educational and welfare services for their
children. Compared with parents who said they had no
carer stress, those who reported five consequences or
feelings of burden were twice as likely to contact primary
health services, three times more likely to use specialist health
services, and five times more likely to seek help from social
services for their child’s difficulties.

### Table 4: Use of services for child by number of burden and stigma items.

| Services used                     | 0%   | 1-2% | 3-4% | 5 or more% | Chi-squared |
|-----------------------------------|------|------|------|------------|-------------|
| Education (e.g., teacher, educational psychologist) | 29.9 | 40.9 | 56.1 | 65.5 | X² = 50.48, df = 3, P < .001 |
| Primary healthcare (e.g., GP, health visitor)      | 25.5 | 32.2 | 40.5 | 52.7 | X² = 29.69, df = 3, P < .001 |
| Specialist healthcare (e.g., Paediatrician)            | 10.4 | 24.0 | 30.1 | 30.3 | X² = 23.91, df = 3, P < .001 |
| Social services (e.g., social worker)                  | 7.9  | 12.5 | 22.0 | 41.8 | X² = 70.15, df = 3, P < .001 |
| **Base**                                             | 164  | 208  | 173  | 165 |             |

**8. Discussion**

8.5. Study Limitations. Although the participation rate of
parents and young people in the survey was high, about
a quarter of sampled households could not be contacted
or refused. Parents who refused to take part or could not
be contacted may have a higher rate of caregiver stress or burden. In addition, there is evidence from previous child psychiatric surveys that rates of childhood psychopathology are higher among nonrespondent families [17, 18], which lead to biased estimates of prevalence of childhood mental disorders. In addition, parents who feel stigmatized may be hesitant to respond to a survey about their child’s behaviour. Even though the data were weighted for nonresponse, it is not possible to assess the magnitude and direction of potential bias in the resulting rates.

8.6. Implications for Future Research. It would have been desirable to ask the caregiver strain questions to all parents in the survey. The parents of most of the children who ended up with the diagnoses of conduct or emotional disorders were asked these questions, but a few cases were missed, namely, those where conduct disorders were diagnosed entirely on the basis of teacher or youth reports and parents did not express any concerns. It seems plausible that these parents would be likely to report low levels of care-giver strain although some might be in conflict with the child’s school about the existence of problems in the school context that were not visible at home. We might therefore have underestimated the level of caregiver burden.

Children’s perceptions of burden or problems would have provided a more comprehensive understanding of the impact of the child’s difficulties at a family unit level. Parenting attitudes, rearing practices, and capacity were not measured; as all have shown to mediate parent and child mental health problems, they might also be important mediators or moderators of the level of strain experienced by parents.

Carrying out longitudinal research in the general population as well as with high-risk families and families attending clinical services will be important in establishing the value of parental burden or strain and its interaction with parenting capacity and response to interventions in predicting child mental health outcomes, or vice versa. A wider conceptualization and measurement of burden to include the perceptions of children, teachers, peers, and other carers would also contribute to planning community and specialist interventions.

Although all the parents who were directed to answer the question on “burden” reported that their children had problems of clinical severity, it would be interesting for future research to also focus on children with conduct and emotional disorders whose parents do not report significant burden or care and thus understand the differences from families who do so and to identify factors that promote resilience in dealing with distress.

9. Conclusions

9.1. Implications for Practice. As the number of children with mental illness is increasing, the numbers of children requiring care from relatives is also growing. Consequently there is an increasing demand to understand the needs of caregivers. Understanding their needs is crucially important for planning interventions and testing the value of programmes to support caregivers [2]. Since parental strain has a detrimental effect on parental health (more worry, depression, physical ill health, and increased smoking and drinking) which in turn may negatively impact on the child’s mental health, it is important to reduce the caregivers’ burden, so that parents can provide sufficient care and maintain their own healthy life [2]. Perception of burden and stigma is real for the parents and should not be ignored and needs to be taken into consideration in treatment plans. It is particularly important that practitioners are sensitive to the high levels of guilt and embarrassment that many parents feel in relation to any psychological difficulties experienced by their child. Feeling blamed by practitioners, whether real or imagined, is likely to impair the therapeutic relationship and may adversely impact on interventions designed to alleviate the child’s or family’s difficulties.

Clinicians need to take into account the mechanisms which underpin parental beliefs and narratives on the nature of burden and stigma. Caregiver stress and burden can be reduced through additional practical support or interventions, such as respite care for the parent rather than the child, enhancing social networks through parent support networks, and encouraging links with self-help organisations for children with similar difficulties. Interventions for the parents, in particular, if they suffer from mental health problems themselves and joint/family interventions which target the causes and impact of burden in the parent-child relationship may improve the situation. Interventions for the parents (parental education, behavioural strategies) may also minimise and prevent burden/impact of child behaviours.

9.2. Focus of Interventions. As it is well established that parental and child distress expressed through a range of mental health problems are interlinked and often underpinned by parenting difficulties, interventions need to focus on reducing such distress among both parents and children, as well as enhancing the quality of family relationships. Indeed, there is growing evidence on the effectiveness of parenting and family interventions at multiple levels, that is, universal community programmes, targeted interventions for high risk families, and those provided at secondary health care level [19, 20]. What the findings of this study illustrate is the importance of recognising, acknowledging, and addressing the burden experienced by caregivers of children with emotional or conduct disorders, in particular, their feelings of stigma, embarrassment, reduced quality of life, and poorer health.

More specifically, clinicians and other professionals involved should adopt a broad assessment framework, irrespective of their theoretical stance, to recognise parents’ and families’ impact of perceived or real burden of care, whether this is primary or secondary to children’s mental health problems. Second, they could reduce or alleviate the practical consequences of burden through family support, respite care, or community activities, depending on their level of need and available resources. Finally, parents’ perceptions and experiences could form the focus of the intervention and become integrated with behavioural or family systemic strategies.
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