REVIEW

Young People's Response to Parental Neurological Disorder: A Structured Review

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Introduction: A significant paucity of literature exists relating to the impact on children of parental neurological disorder, with the exception of multiple sclerosis. The wider literature in this field (parental cancer, depression, alcoholism, HIV/AIDS) exhibits the many potential challenges young people might experience during serious parental illness. Given this, a literature review of parental neurological disorder is long overdue.

Methods: This review is structured around the World Health Organisation (WHO) classification of neurological disorders. The WHO identifies 10 common neurological disorders; dementia, epilepsy, headache, multiple sclerosis, neuroinfections, neurological disorders associated with malnutrition, pain associated with neurological disorders, Parkinson's disease, stroke, and traumatic brain injury. A comprehensive search of the MEDLINE database was performed using key terms for each of the 10 conditions. Results for each condition were divided in to "negative", "positive and/or neutral" and "other" child responses.

Results: The search yielded a total of 6247 titles, of which 184 underwent a full-text assessment. Sixty-five met all eligibility criteria and were thus included in the review. A number of negative issues emerged across parental conditions including the prevalence of child mood disorders, parent-child role reversal, children's need for information on the parental condition, the importance of family cohesion, the negative effect of parental psychopathology and differences between male and female children. A limited number of positive outcomes were evident in a minority of parental conditions. Outcomes measured and methodologies employed were highly heterogeneous.

Conclusion: Children generally respond negatively to parental neurological disorder. Responses varied between neurological disorders, suggesting the need for parental disease-specific guidance and clinical management where required.

Keywords: parental illness, neurological disorder, young people, children, parent, World Health Organisation, outcomes, review

Introduction

It has often been overlooked that illness has a wider reaching impact than being confined to the individuals affected themselves.[1,2] Partners and close relatives also experience difficulties resulting from an illness, but the effects on the offspring of those diagnosed has, until recently, been largely neglected. Approximately 10% of children have a chronically ill parent[3] and these children can potentially experience unique and complex challenges when faced with their parent's condition. Current research emphasises the importance of specific variables such as the child's family environment, their age, gender,[4] and the specific nature and course of the parental condition.[5] These challenges can lead to a variety of child responses, both positive,

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such as coping and independence,[6] and negative, such as psychosocial maladjustment.[4]

In 2005, neurological disorders contributed to 10.9% and 4.5% of the global burden of disease in high- and low-income countries, respectively. Ultimately, they were responsible for 6.39% of the total disability-adjusted life years in 2015.[7] Neurological conditions are often immensely debilitating, with many disorders showing a chronic progression that is lifelong, but not ultimately fatal.[7] The disorders affect a diverse range of ages, with diseases classically associated with ageing, such as dementia, also occurring in a minority of younger patients. Many of those affected are, therefore, of child-rearing age. Over twenty years ago, the World Health Organisation's (WHO) global initiative on neurology and public health[8] identified a general lack of information on the burden of neurological disorders. Specifically, a great paucity of literature still exists relating to the impact on children of parental neurological illness. The wider literature in this field (parental cancer, depression, alcoholism, HIV/AIDS[9–11]) exhibits the many potential challenges young people are faced with during serious parental illness. Given this, a literature review of parental neurological illness is long overdue.

Aim

The purpose of this review is to scope the existing literature using a structured approach in order to determine the characteristics of children's experiences of a range of parental neurological illnesses. It is intended that results will highlight current knowledge and research needs, as well as provide valuable information for clinicians and service providers. This review focuses on all children of affected parents, regardless of their caring status. A much wider literature is available regarding the specific impact of fulfilling the role of carer as a child[12] and this is not addressed here.

World Health Organisation Classification of Neurological Disorders

This review is structured around the World Health Organisation's (WHO) classification of neurological disorders. A 2006 report published by the WHO identified 10 neurological disorders that were said to "represent a substantial component of the global burden of neurological disorders": dementia, epilepsy, headache disorders, neurological disorders associated with malnutrition, multiple sclerosis, neuroinfections, pain associated with neurological disorders,

Parkinson's disease, stroke, and traumatic brain injury.[7] These conditions will be briefly introduced, in order to provide some context for the relevant child responses.

Dementia is an umbrella term used to describe a decline in multiple higher cortical functions such as memory, learning and comprehension,[7] as well as behavioural changes.[13] A minor proportion of patients are diagnosed before the age of 65, and are thus classified as "early onset" cases.[14]

Epilepsy describes conditions involving recurrent seizures, defined as "transient occurrences of signs and/or symptoms due to abnormal or excessive synchronous neuronal activity in the brain".[15] Epilepsy affects all ages and both sexes, including those of child-bearing age.

Headache disorders include cluster headache, tension-type headache, and medication-overuse headache. Those affected tend to be in the 20–40 year age group; often young families are particularly vulnerable. Migraine is the most extensively studied disorder, although not the most common, and affects women (and consequently mothers) far more than men.[16]

Neurological disorders associated with malnutrition are a largely preventable global problem resulting from the inadequate availability of food in many areas of the world.[7] Malnutrition disturbs many aspects of health including the nervous system and cognitive development, can affect people of all ages, and ultimately lead to death. Specific neurological disorders include polyneuropathy, progressive myelopathy, and pellagra including dementia and depression.[7,18]

Multiple sclerosis (MS) is an autoimmune condition responsible for gradual and progressive physical disability, often accompanied by cognitive decline. Additional symptoms can include chronic fatigue and depression. Women are affected significantly more than men, where its onset tends to occur at childbearing age between 20 and 40 years.[7,17]

Neuroinfections is a term used to denote infectious diseases affecting the nervous system. In this category, the WHO includes: HIV/AIDS, viral encephalitis, poliomyelitis, tuberculosis, leprosy neuropathy, bacterial meningitis, tetanus, neurocysticercosis, cerebral malaria, toxoplasmosis, American/African trypanosomiasis, schistosomiasis and hydatidosis.[7] Parental HIV/AIDs is not included here due to the number of recent reviews conducted,[19–22] which readers may wish to refer to.

Pain associated with neurological disorders can be either direct neuropathic pain, or nervous system disorders that indirectly cause pain, where pain is defined as "an unpleasant sensory and emotional experience associated

with actual or potential tissue damage".[23] Direct neuropathic pain is the consequence of neurological conditions that damage pathways that transmit information about painful stimuli in the peripheral or central nervous system. Alternatively, indirectly caused pain is a result of a condition that causes secondary activation of pain pathways, eg, musculoskeletal pain in Parkinson's disease.[7]

Parkinson's disease (PD) is a chronic progressive condition characterised by motor symptoms such as tremor and rigidity.[7] Between 5% and 10% of those affected will develop PD before the age of 40 (although many will remain undiagnosed), and one in seven is diagnosed before the age of 50. Consequently, a number of those affected are likely to be raising young and/or adolescent children.[24,25]

Stroke can be defined as a rapid loss of neurological function as a result of haemorrhage or ischaemia. It is the third most common cause of death behind heart disease and cancer in most developed countries.[7] Stroke can occur at any age with resultant features varying in severity, from mild weakness or tingling in the limbs, to major paralysis. The majority of stroke survivors show a degree of recovery over time, but only a minority return to their pre-stroke health state.[26]

Traumatic brain injury (TBI) is the leading cause of disability worldwide in those under the age of 40.[7] Many young families are thus burdened considerably.[27] The severity of TBI ranges greatly, leading to a diversity of patient outcomes with an often unpredictable recovery course.

Methods
Literature Search
A preliminary search indicated that the earliest relevant paper was published in 1984 and consequently the review searched the period from 1984 to October 2018. The PubMed interface was used to search the MEDLINE database. Each of the 10 aforementioned disorders was individually searched, with the search terms taking the general format of: "children AND parent AND condition". Where the WHO classification subdivided a single condition in to smaller categories, these sub-conditions were also searched in the database. The Web of Knowledge database was additionally searched for "children AND parent AND Parkinson's disease" and results were then compared to those obtained from MEDLINE. This enabled validation of the original findings, and the assurance that no new studies were identified for inclusion.

Where relevant, methodologically sound systematic reviews of any of the ten disorders published within the last 5 years were summarised. The review process, as outlined above, was subsequently commenced 1 year prior to the submission date of the previous systematic review.

Eligibility Criteria
Peer-reviewed, full-text published studies were included where they met the following criteria: (1) children or youths aged 24 or below (in accordance with the United Nations' definition of "youth")[28] were included or referenced by proxy as part of the study; (2) results were reported in either a qualitative or quantitative analysis; (3) at least one parent was diagnosed with at least one of the aforementioned 10 neurological conditions, or a condition mentioned as a subsection within one of the 10 categories; and (4) the study was published in English. Due to the limited literature in this field, the inclusion criteria was designed to include a wide variety of methodologies including less reliable proxy reports (where the respondent is an individual other than the specific child in question). Data such as comments, conference abstracts, and opinion pieces were not included.

Data Extraction and Analysis
The utilisation of a data extraction form (see Figure 1) enabled the selection of relevant information from included studies, and an easier cross-comparison upon analysis. This was based on, and adapted from, a previously published review included in this report.[29] All potentially eligible studies were then reviewed in a full-text analysis. In this instance, meta-analysis was not possible due to the diverse range of methodologies, both qualitative and quantitative, incorporated in the included studies. Outcomes measured were also highly heterogeneous. Consequently, narrative analyses were performed, where results from each condition were divided in to "negative", "positive and/or neutral" and "other" child responses, thus facilitating an easier cross-comparison between results.

Results
Literature Search
The numbers of studies returned by the initial searches of each condition, and the numbers undergoing subsequent exclusion and inclusion from the study, are summarised in Table 1. From the individual searches of all 10 conditions, a total of 6247 citations were returned. These citations underwent a title (and, where necessary, abstract) screening stage; here, 6064 were excluded, as they were not relevant to this review based of the previously outlined inclusion criteria. The

Publication date:	
Authors and reference:	
Country reported:	
Study type (i.e. qualitative / quantitative):	
Number and age of participants:	
Respondent (i.e. child / parent):	
Outcomes measured:	
Main findings:	

Figure 1 Data extraction form used for review process. Data from Razaz et al.[29]

remaining 183 underwent a full-text assessment for eligibility using the criteria, of which 118 were excluded. Reasons for their exclusion are given in Table 2. Sixty-five studies were thus deemed eligible, and included in this review.

Outcomes Measured

Outcomes measured between studies varied greatly, for example, from parental psychopathology and child educational outcomes, to parental marital satisfaction and child behaviour. Some included studies did not focus on any particular outcomes at all, instead facilitating an "open" interview where the children were simply able to recount their experiences in their preferred manner.

Overview of results

The complete findings from all included studies are presented in Table 3. Child mood and anxiety disorders were common, with studies from the dementia,[39] headache,[55,58] multiple sclerosis,[64–66] neuroinfections,[74] Parkinson's disease[76,77] and traumatic brain injury[89,92] searches all identifying an increased risk. Three of the 10 conditions also observed significant parent-child role reversal.[30,33,38,39,53,57,76] Furthermore, many children sought to be well-informed regarding their parent's condition and communicated with relevant services. This communication was evident in six conditions,[34,41,49,52,71,73,78,82,85,94] but satisfaction with the information and services received was variable.[33,37,50] Family cohesion, including the parental marital relationship,

Table 1 Numbers of Records Retrieved, Excluded and Included Across All Conditions

Condition	Number of Records Retrieved from Initial Search	Number of Records Excluded Post Title-Screening Stage	Number of Full-Text Articles Assessed for Eligibility	Number of Articles Excluded	Number of Articles Retained
Dementia	473	436	37	25	12
Epilepsy	2313	2278	35	24	11
Headache	683	653	30	22	8
Neurological disorders associated with malnutrition	26	26	0	0	0
Multiple sclerosis	69	54	15	2	13
Neuroinfections	1585	1580	5	3	2
Pain associated with neurological disorders	104	100	4	4	0
Parkinson's disease	67	54	13	10	3
Stroke	415	388	27	17	10
Traumatic brain injury	512	495	17	11	6
Total	6247	6064	183	118	65

Table 2 Articles Excluded at Full-Text Screening Stage

Condition	Number of Studies Excluded	Reasons for Exclusion (Number Excluded)
Dementia	25	Focus on caregivers (6) Children >24 years old (10) Focus on other family members' responses (2) Focus on support service delivery (2) Many illnesses included (2) Could not access (not fully published) (2) No ages of children given (1)
Epilepsy	24	Focus on epileptic parent response, not children (2) Focus on AED effects only (8) More conditions investigated (1) Article unavailable due to age/not fully published (2) Review article of already included studies (1) Focus on childhood epilepsy (1)
Headache	22	Focus on child headache (12) Validation of questionnaire outcome measure (1) Focus on inheritance (6) Impact on spouse (1) Focus on child medication use (1) Focus on affected parent's headache (1)
Neurological disorders associated with malnutrition	0	
Multiple sclerosis	2	Study focus on child caregiving (2)
Neuroinfections	3	Not published in English (1) Focus on sponsorship, not child response (1) Responses of other family members (1)
Pain associated with neurological disorders	4	Focus on other conditions than those specified (3) Child pain (1)
Parkinson's disease	10	Focus on caregivers (4) Validation of questionnaire outcome measure (1) Grey literature (conference abstracts) (3) Not published in English (1) Focus on inheritance (1)
Stroke	17	Child stroke (5) Focus on child caregiving (5) Validation of questionnaire outcome measure (1) Other conditions investigated (2) Focus on parenting (2) Focus on inheritance/risk factors (2)
Traumatic Brain Injury	11	Child TBI (1) Focus on parent response (3) Focus on stroke (included in stroke section) (1) Review of already included data (1) Response of other family members (4) Article not fully published (1)

was also a significant factor in child responses for half of the 10 conditions.[48,51,58,68,78,79,81,88] Parental psychopathology was also associated with poor child responses and stress.[60,65,66,70,79-81,83,91,93] Female children were seen to be at an increased risk of psychiatric disorders, stress, or behavioural problems compared to males in four

Table 3 Overview of Results for All Included Studies

Condition[ref]	Negative Child Responses	Positive/Neutral Child Responses	Other Responses
Dementia[30–41]	- Significant general stress and emotional burden - Grief and loss very prominent as parents are 'sliding away' - Parent-child role reversal, including household responsibilities - 1/3 children experience mood disorders - Feelings of marginalisation - Significant life events/times of change most overwhelming, particularly moving out often leading to breakdown of family relationships - Feeling uncertain for the future	- Often employ positive coping mechanisms, such as detachment, by leaving home - Accessing support services perceived as self-empowering - Label of 'dementia' helpful in child disclosing the condition to others - Some families closer than before - Minority of young people exhibit high levels of resilience	- Social support services vitally important but often inadequate - Education about condition vital - Children often play large role in diagnosis such as noticing signs - Unhelpful to state parent is 'still the same person' as gives expectations children should feel the same way towards parent
Epilepsy[42–52]	- Lower child IQ predicted by parental education, maternal IQ, anti-epileptic drug exposure - Low child IQ predicted by family/social risk factors (lack of discipline, stimulation or maternal involvement; low socioeconomic status) when child was also exposed to prenatal AED or parental seizures - Social risk factors increase long term cognitive adverse effects, including psycholinguistic abilities - High seizure rate associated with poor quality of upbringing - Increased child psychopathology risk where marital discord or disturbed parental behaviour occurs - Discord often causes neurotic disturbances, eg, tics/sleep problems - Problems with social functioning including at school - Fears include parental loss, developing epilepsy themselves - Poor development at 1 year continues at 6 years	- Acceptable levels of communication regarding epilepsy, satisfied with information received - Majority of children sufficiently socially adapted - Older children often develop independence from parent to cope	- Most children know about parental epilepsy before parent's first seizure - Most poorly adjusted children have epilepsy concealed until they had witnessed first seizure - Children find communication easier than parents - Learning about epilepsy best when involving a medical professional, taking an individual approach to child concern
Headache[53–60]	- Affected parents spend less time with their children and let them down - Children report reduced parental involvement in their education - Most negative experiences occur in children deprived of parental care - Poorer school attendance - Higher rates of abnormal internalising disorders, sadness, maladjustment, behavioural problems and delinquency - Younger children experience school difficulties - Older children experience adverse social relationships - Parent-child role reversal (eg, meal preparation), with higher rates of parental disability increasing this reversal - Maternal psychopathology negatively correlates with child self-esteem and quality of life - Greater burden seen in chronic migraine (vs. episodic)	- No significant effect on child psychological and family functioning - Majority (66%) of younger children react positively and 83% of older children are understanding, with only minority being hostile	- Family cohesion important; greater family cohesion associated with lower impact of headache on daily activities

(Continued)

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Table 3 (Continued).

Condition[ref]	Negative Child Responses	Positive/Neutral Child Responses	Other Responses
Multiple Sclerosis[61–73]	- Higher rates of mood/anxiety disorders - When co-exisiting parental psychopathology exists, there is increased risk of child mental health disorder, language and cognitive development vulnerability and child externalising disorders - Lower rate of child employment at age 30	- Little difference in educational outcomes, early childhood development and social adjustment outcomes compared to controls - Low risk of social vulnerability and peer relationship problems	- Family functioning essential for child adjustment - Children must be well-informed - Coping strategies involve maintaining control which increases life satisfaction - Children strive for a balance between parental care and realising their own goals
Neuroinfections (leprosy only)[74,75]	- Higher rates of depression, lower self-esteem, inferior quality of life	- Experience of friends and school similar to controls - No significant behavioural changes	
Parkinson's Disease[76–78]	- Parent-child role reversal - Inferior adjustment seen in children with no siblings - Increased rates of depression in affected children - Female children have lower self-esteem than male	- Providing sufficient information about Parkinson's would improve child adjustment	- Impact of Parkinson's increases with disease duration - Similar degree of well-being seen between children affected by parental PD and MS
Stroke[79–84]	- Children may hide feelings of grief to protect the ill parent and parents may underestimate the child's emotional stress - Increased behavioural problems, predicted by younger age - Negative reactions occur in minority; 16and 13% show externalising and internalising disorders respectively - 46% of children have post-traumatic stress symptoms - Female gender predictive of behaviour problems and increased stress - Depressive symptoms and cognitive disorder level of healthy parent increase child stress - Depression, living limitations and life satisfaction of ill parent also increase child stress - Aphasia in parent the 'most dramatic loss' - Child stress related to quality of parental relationship	- Most children experience little harm, good care, and do well - Children feel more needed and mature, have more responsibility - Improvement seen from 2–12 months post-stroke in internalising disorders, depression, and child health - Externalising disorders do not change over time - Healthy parent depressive symptoms improve over time	- Lack of communication endangers parent-child relationship - Increased levels of communication seen in larger, supportive families, families in which parent spends little time at home and families with low levels of healthy parent psychopathology - No correlation between parental disability and child adjustment - Marital relationship not related to child stress - Young age unrelated to child stress
Traumatic Brain Injury[85–94]	- Increased risk of psychiatric disorders, particularly depression, and increased use of child psychiatric services - Males have increased risk of externalising disorders, females have increased risk of developmental psychiatric disorders - Increased behavioural problems - Children employ unhelpful coping strategies such as avoidance and suppression - Healthy parent stress associated with higher levels of post-traumatic stress and emotional and behavioural problems in child - Depression of healthy parent and affected parent's gender associated with poor child behaviour	- Some children employ helpful coping strategies, eg, talking to peers - No significant behavioural differences when compared to peers	- Require more information/advice - No association between affected parent's disability level and child well-being - Less parental emphasis on discipline - Affected parent lacks involvement in parenting - Reduced parenting performance correlates with poor behavioural outcomes

conditions.[78–80,83,89] Multiple sclerosis was the only condition with a recent systematic review,[33] concluding that affected children had generally negative psychosocial experiences.

There were, however, some positive responses noted. These were limited but most evident in children of parental stroke, multiple sclerosis and dementia. Many of the children affected by parental stroke were seen to "do well long term", with some responses even improving over time from 2 to 12 months.[81–83] For parental multiple sclerosis, children seemed to show lower risks of social vulnerability.[62,66,72] Positive responses tended to focus around the employment of useful coping mechanisms[34,39,40] and the development of resilience in parental dementia.[39]

Discussion
Discussion by Parental Neurological Condition
The following commences with a summary of the potential implications of each parental condition for children, followed by a more general discussion of the results. Some limitations of the review process are subsequently highlighted, concluding with implications and recommendations based on the review results.

Dementia
The unique feeling of grief in children with dementia-affected parents was not seen in the other nine included neurological conditions.[32,33,38,39] Whilst other conditions may be chronic and debilitating, no other condition causes such a profound behavioural change in the parent as dementia does. Parents are said to "slide away".[37] The availability of support services for parental loss whilst the parent is still alive may aid children through this grieving process. It may also be important to provide support to those children who are going through important life changes such as leaving the parental home or going to university, as such changes can cause significant disruption to the family unit.[30,31]

Epilepsy
The effects of in utero exposure to antiepileptic drugs (AEDs) accounted for most of the epilepsy research, of which most was excluded from this review. In the few-included studies that had a component exploring this, there was no clear distinction between the effects of AEDs on children, and child responses occurring as a result of solely social and psychological factors.[43–47] It thus remains difficult to conclude the cause of specific child responses. Moreover, higher parental seizure frequency appears to be associated with greater impact on child outcomes.[46] Responses could consequently change, dependent on the epilepsy severity. Additionally, epilepsy results from a diverse range of aetiologies, and the correlation between the aetiology/cause of epilepsy and the child response has so far been neglected.

Headache Disorders
Extrapolation of the results to include all headache disorders is inappropriate, as five of the seven included studies examined only parental migraine. It is most evident from included studies that headache can lead to a lack of parental care.[53–55] There may be potential for this to be a causative factor in other observed outcomes such as school interference, internalising disorders, and parent-child role reversal. More support with parenting skills may thus improve child outcomes. Furthermore, the lone study that observed little effect on child functioning[56] noted that their participants were recruited from the community (rather than clinics), where disability rates and child burden are less common.

Neurological Disorders Associated with Malnutrition
With no studies identified in this review, the lack of literature is most likely a result of the nature of malnutrition, which remains a problem in the developing world. Scarce resources are unlikely to be utilised in research relating to child responses to parental malnutrition when the problem of malnutrition itself has yet to be fully tackled.

Multiple Sclerosis
A diverse range of child responses to parental MS were observed, which may be a result of the variable nature of the condition. It is striking that recent evidence suggests more positive social outcomes for children than previously suggested.[66,67,72] However, parental mental health appears to have a profound impact on children's own emotional well-being, suggesting that parental mental health screening could be a useful tool to identify children most at risk themselves.

Neuroinfections
The virtual eradication of most neuroinfections in many first world nations has led to their effects being largely overlooked in the developing world. This is reflected in the paucity of literature reported here. Whilst negative psychosomatic experiences were found in children of parents

with leprosy in one study,[74] there were no behavioural changes observed in another.[75] The participants in the latter study happened to be living in a care facility away from their parent, therefore their living situation, as opposed to the leprosy itself, may be the causative factor that facilitates behaviour similar to unaffected children.

Pain Associated with Neurological Disorders

A recent publication of Morley et al[2] highlights the small field of literature concerning child response to more general chronic pain, something reflected in the results reported here, with no studies identified relating to parental neurological disorders associated with pain. Future research is required in this area in order to identify its potential impact on the offspring of affected parents.

Parkinson's Disease

A unique finding in parental PD is the negative impact of a reduced number of siblings on adjustment.[76] One study also observed that children of different ages perceived different problems[78] which would be useful to follow up using longitudinal study designs. Furthermore, the impact of parental PD on children tends to increase with disease duration,[78] perhaps due to its progressive nature.

Stroke

A largely positive response of children to parental stroke is apparent when compared to other parental conditions. This may be due to the nature of the condition itself; unlike other neurological disorders such as dementia, stroke rehabilitation is generally not degenerative, thus enabling children to adjust to the parental condition over time. The greatest risk factors of child maladjustment identified were female gender and parental status/stress, with this highlighting the need for a holistic family-orientated approach, when assessing the effect of parental stroke.

Traumatic Brain Injury

Parental TBI represented a negative picture of child responses. This was contrary to stroke. This could be due to the cause of the disorder: in TBI, "accidents" such as road collisions are a major cause,[7] leading children to become angry and blame others. TBI may also be more severe, acute and restricting for the parent than other neurological disorders. By contrast, stroke may be deemed as more of an illness, and thus its causes seem more elusive. This may instead facilitate acceptance over time. One study of parental TBI did, however, find there to be no significant difference in child behavioural problems compared to controls.[92] This study observed that affected parents often reported a lack of emphasis on discipline, perhaps leading them to believe lower standards of child behaviour are deemed as acceptable.

General Discussion

The review identified the use of predominantly cross-sectional study designs, which have particular limitations given that child responses are often reported to differ between age groups.[60,78,80] There may also be natural variations at different stages of a child's development, and cross-sectional studies might not account for a response that may not be wholly down to parental illness, but due to the more commonplace challenges of growing up.

Furthermore, a total of eight studies included in this review were fully proxy, with many more having a proxy element. Dementia was the only condition to have no proxy studies included in its results. It has been found that there is a greater degree of agreement between parent and child ratings of health-related quality of life (HRQoL) when they refer to observable functioning such as physical health, as opposed to non-observable functioning such as emotional/social HRQoL.[95,96] This may significantly influence results obtained across the included studies, as most contained social or emotional elements. One study reported that children often hid their negative feelings to protect their affected parent;[86] this could also occur in the context of study participation if a parent is taking part alongside their child.

The larger cohorts used in the studies assessing parental headache, as opposed to the smaller cohorts in dementia and stroke, may reflect a number of factors. Headache is far more prevalent than young-onset dementia or stroke, and its associated lack of mortality may result in children experiencing their entire youth with an affected parent whose condition does not become fatal. Both of these factors simply produce a larger pool of potential participants.

Studies focusing on parental dementia used exclusively qualitative methods. Whilst these methods can be useful in identifying themes and concepts in the early stages of research,[97] they do not provide accurate, objective assessment of responses and cannot be generalised to the wider population in question. In a similar vein, the use of control groups was not common. These were seen most often within the MS category. This may simply be due to the more advanced stages of research in this parental condition. Such a study design enables a more objective comparison of child responses to unaffected control children. It

is also notable that many studies did not control for variables such as socioeconomic status that are likely to play a role in determining overall child outcomes.

Epilepsy studies were markedly older than all other conditions, with the first published in 1984. It is important to consider the differences in society and in pressures on young people today, when compared with over 30 years ago,[98] and the implications for changes in child responses. These differences may, in turn, influence child responses to parental illness. They may include factors such as the widespread use of technology facilitating improved access to information, and the opportunity to connect with other young people experiencing similar issues, and the destigmatisation of mental health issues enabling more open conversations regarding child psychopathology. Furthermore, only 10 of the 65 studies were carried out in the UK; this is vital to consider when informing guidelines intended for a particular population.

Limitations of the Structured Review Process

The structured review process itself does come with some inherent limitations. For example, it is difficult to account for publication bias. Furthermore, the process of study inclusion may have an element of subjectivity. The use of a data extraction form aimed to make this selection process as objective as possible. Additionally, the large range of outcome measures used did not lend itself to a simple and objective cross-comparison of results across different conditions. Interpretation of the results gleaned by the review is also somewhat limited due to the varying methodological quality of included studies. Objective quality appraisal of studies was challenging, as there is no standard for quality appraisal of observational studies in a systematic review.[99] Instead, the use of more general variables (cohort size, the use of controls, proxy respondents, quantitative measurements and longitudinal design) enabled a surface quality assessment.

Implications and Future Recommendations

The varying child responses across parental disorders suggest that the production of broad, sweeping guidelines produced for children experiencing parental illness may be inappropriate. Instead, clinicians and service providers should recognise the differing nature of responses across conditions and produce individualised recommendations accordingly. The association between parental psychopathology and negative child responses highlights the need to produce family-focused guidelines.

Recommendations for future research include longitudinal and population-based studies. Quantitative measures would also provide a more objective approach, where standardised measures can be used to fit varying experiences of children into a limited set of categories, thereby enabling easier comparison. Outcome measures may thus need to be developed and validated for this purpose, as well as to identify children most at risk of adverse outcomes. Furthermore, conditions such as parental neurological pain and neuroinfections require research to begin. For the latter, child responses to widespread tropical neuroinfections, such as malaria, would be a useful start due to their high prevalence.

Conclusions

The comparison of child responses to a range of parental neurological disorders is challenging. The range of outcome measures, and methodological study designs, used across all 10 conditions varied greatly and thus only tentative conclusions can be drawn. This variation highlights the need for an individualised approach to children from a clinical perspective. From this review, it is evident that children generally respond negatively to parental neurological disorder. This is particularly apparent in the areas of child psychopathology, parent-child role reversal and behavioural problems, where parental psychopathology, female gender, and disrupted family cohesion were common risk factors. There were, however, some positive responses, which were most evident in parental stroke, multiple sclerosis and dementia. The quality of included studies varied greatly, with many containing significant methodological limitations. Future research should aim to clarify these findings, by employing more robust methods of longitudinal and population-based study design to identify those children most at risk of adverse responses.

Author Contributions

All authors made substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data; took part in drafting the article or revising it critically for important intellectual content; gave final approval of the version to be published; and agree to be accountable for all aspects of the work.

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