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The psychosocial impact of rare diseases among children and adolescents attending mainstream schools in Western Australia

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ABSTRACT

Living with a long-term medical condition is associated with heightened risk for mental health and psychosocial difficulties, but further research is required on this risk for children and adolescents with a rare disease in the educational setting. The aim of this study is to describe parents' perceptions of the psychosocial impact of rare diseases on their school-aged children in Western Australia. A cross-sectional survey of 41 parents of school-aged children and adolescents diagnosed with a rare disease completed an online questionnaire. Questions related to their perceptions of health-related stigma, bullying, social competencies and mental health difficulties faced by their child. Results showed that stigmatisation was experienced by 75.6% of participants, and almost half (46.4%) reported their child was bullied. In this sample, parents reported high sensory (vision and hearing) abilities, but low to moderate self-care competence in relation to social activities and peer relations. Almost half of the respondents (43.9%) reported mental health difficulties among their children. Children and adolescents with a rare disease have unique psychological and social issues. These findings highlight the need for greater efforts to meet the diverse psychosocial, physical and emotional needs of children diagnosed with a rare disease who attend mainstream schools in Western Australia.

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Introduction

Rare diseases are a broad range of life-threatening or chronically debilitating conditions that have no cure, cannot be prevented, and have no effective treatment (Department of Health 2015). The term rare diseases encompass different types of conditions including genetic diseases or syndromes that collectively affect up to 8% of Australia's population; in Australia, there are over 2 million people, including 400,000 children, living with a rare disease (Elliott and Zurynski 2015).

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It is well established that living with a rare disease is often associated with negative impacts on both children and their families (Elliott and Zurynski 2015; Picci et al. 2015). Much of the rare disease burden in Australia is associated with parents' feelings of isolation, lacking adequate services, financial cost, and misdiagnoses (Jaffe et al. 2010; Anderson, Elliott, and Zurynski 2013). Diagnostic delay is a significant problem faced by parents and healthcare providers in Australia (Zurynski, Gonzalez, et al. 2017; Zurynski, Deverell, et al. 2017). The burden of caring for a child with rare diseases includes physical, financial and psychological stress (Department of Health 2015).

The impact of psychological stress among children with chronic diseases has been reported in the literature. Evidence suggests that children living with rare diseases have reduced health-related quality of life and high levels of emotional difficulties (Cohen and Biesecker 2010; Cole et al. 2013). The complexity of care needs among children means that living with a rare disease often has a major impact on schooling and other social experiences. The school experiences of having an ongoing chronic condition have been studied elsewhere (Lum et al. 2019) and findings suggest that children with chronic conditions experience negative outcomes in schools. For children with rare diseases, school experiences such as absenteeism, inaccessibility of educational facilities, missing out on physical education (sports) and academic activities have been reported (Verger et al. 2020). International studies show that children and adolescents living with long-term conditions are at greater risk of being bullied compared to their healthy peers (Sentenac, Gavin, et al. 2011; Sentenac, Arnaud, et al. 2011; Pittet et al. 2010). Bullying is a relationship problem characterised by intentional and repetitive behaviours intended to cause physical or emotional harm by a person/perpetrator with higher power than the victim. Bullying can be physical (verbal, aggression) or social (cyberbullying or social exclusion) (Olweus 2013; Craig, Pepler, and Blais 2007). Much of the bullying that occur at school are exhibited in face-to-face verbal harassment or physical aggression and cyberbullying or social exclusion (Sentenac, Gavin, et al. 2011; Ford et al. 2017). Health-related stigma is another potentially negative consequence of a rare disease (Joachim and Acorn 2000). Health-related stigma is a social process characterised by social exclusion, rejection, discrimination, devaluation and emotional reaction as a result of one's health problem (Weiss, Ramakrishna, and Somma 2006; Link and Phelan 2006). It has a negative impact on the individual and family's welfare (Sentenac et al. 2011).

In Australia, there is a huge emphasis on inclusive education in all public schools since the 1990s (Anderson and Boyle 2015). Therefore, having children with rare and chronic diseases in mainstream public schools is a common practice. However, research remains scarce on the psychosocial impact of rare diseases on children and adolescents and its effect on their school experiences. Additionally, there has been a recent call for rare diseases to be recognised as a health priority in Australia (Walker et al. 2017). The Western Australia Rare Disease Strategic Framework 2015–2018 also highlights the need for further research to inform further development of government policies for rare diseases in the state. To better understand the psychosocial impact of rare diseases among school-aged children, we explored parental perceptions of psychological, social and school adjustment of children and adolescents diagnosed with a rare disease in a mainstream school in Western Australia.

Methods

Study design

This cross-sectional study was conducted as part of a larger online survey conducted on the well-being and school experiences of children and adolescents with a range of chronic conditions, namely type 1 diabetes, hearing loss, cystic fibrosis and rare diseases, as reported by their parents (Fried et al. 2018).

Ethical consideration

Ethics approval was granted by the Princess Margaret Hospital Human Research Ethics Committee. The online survey was accessed via a web link. Parents received detailed information about the study before deciding to participate. They were unable to proceed with the survey without consenting to the research. The survey took approximately 20–30 minutes to complete and participants were required to complete the survey in one sitting.

Participants

The sample was a convenience sample of self-identified parents or guardians caring for a child or adolescent diagnosed with a rare disease. Inclusion criteria included parents of a child or adolescent (6–18 years) diagnosed with a rare disease and attending a mainstream school in Western Australia (including specialist units for deaf and hard of hearing children which may be attached to a mainstream school). Overall, 41 parents (mainly mothers) completed the survey.

Procedure

Initial recruitment for this study involved convenience sampling and snowball recruitment techniques. Recruitment tools included posters, cards, and advertisements at the Genetic Services Clinics at Princess Margaret Hospital for Children (now Perth Children's Hospital). Advertising was also conducted through Genetic and Rare Disease Network, Rare Voices WA, Genetic Services WA, Office of Population Health Genomics, Children Tumour Foundation, Australian Rare Chromosome Awareness Network, Clefypals, Charge Syndrome Association, VCFS 22q11 Foundation, Neurofibromatosis Association WA Inc, Short Statured People of Australia Inc. (Achondroplasia), Muscular Dystrophy WA and Duchenne Foundation Australia, Kalparrin (a not-for-profit organisation supporting families with a child with disabilities of special needs located at Princess Margaret Hospital) and the Telethon Kids Institute's social media platforms. The School of Special Educational Needs: Medical and Mental Health also assisted with recruitment. Due to the nature of the sampling, the rate of recruitment cannot be calculated.

Measures

Demographic data for the children (age, gender, school grade and rare disease diagnosis) and parents (relationship with child, employment status and family income level) were

collected. Parent stigma was indexed on the Parent Stigma Scale (PSC), a 5-item tool that measures the parents' level of perceived stigma. Parents reported their perception of their child's stigma on the 5-point Likert scale. The PSC is a validated tool with a Cronbach alpha of 0.79 (Austin et al. 2004). The Revised Olweus Bully/Victim Questionnaire (OBVQ) is a 9-item validated tool that measures aspects of bullying in schools in three areas – the intention to harm the victim, the repetitive nature of bullying and the imbalance in power between the victim and the perpetrator(s) (Olweus 1996). Its internal validity and reliability have been confirmed by Kyriakides, Kaloyirou, and Lindsay (2006). The Index of Social Competence (ISC) is a checklist covering 15 adaptive behaviour domains in 4 subscales of overall competence – additional handicaps, communication skills, self-care, and community skills. The ISC has shown internal consistency to distinguish between people with low or high competence ability (McEvoy and Dagnan 1993). The Strengths and Difficulties Questionnaire (SDQ) was used to index mental health. It is a 25-item tool that measures the child's emotional and behavioural difficulties on 5 scales – emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial (positive social) behaviour. We used the parent report extended version for children (4–10 years) and adolescents (11–17 years) (Goodman 2001). This extended version includes an impact section to measure chronicity, distress, social impairment and burden to others. The SDQ has been widely validated with a Cronbach alpha of 0.73. It has also shown good specificity 94.6% (95% CI 94.1–95.1%) and sensitivity 63.3% (59.7–66.9%) in describing the prosocial behaviour and psychopathological outcomes among children aged 3–16 years (Goodman 2001).

Data analysis

The analysis was conducted using SPSS (Version 24.0). Descriptive statistics were reported for the PSC, OBVQ, ISC and SDQ scores. The Mann–Whitney *U*-test was used to explore significant differences or otherwise between the SDQ scale scores and children's gender and age group (primary or secondary school), as the data were non-normal ($p < .05$). Correlational analysis was conducted to establish associations among the five SDQ scales. An independent *t*-test was used to compare the SDQ scores with Australian normative data from Mellor (2005). Chi-square test (χ^2) of independence was performed to analyse associations between the OBVQ and PSC scores across the child's gender and age group (primary or secondary school).

Results

Participant demographic characteristics

A total of 41 parents (all mothers) completed the online survey. The mean age in years for children in the primary school group was 7.56 ($SD = 1.42$) and 13.00 ($SD = 1.93$) for the high school group (overall mean was 10.61; $SD = 3.22$). Demographic data are presented in Table 1. We report a broad illness category to protect the anonymity of the participants' children due to the small sample size and rareness of their diseases in the local community.

Table 1. Sociodemographic characteristics of parents and children sample ($n = 41$).

Variable	<i>N</i>	%
<i>Caregivers' demographics</i>		
Combined income (per week)		
Below median (<AUD 2000)	13	31.71
Above median (>AUD 2000)	20	48.78
Non-response	8	19.51
<i>Children demographics</i>		
Age (years)		
Primary (6–10)	18	43.90
High school (11–17)	23	56.10
Gender		
Boy	19	46.30
Girl	22	53.70
Illness category		
Musculoskeletal diseases	12	29.30
Blood/oncology diseases	5	12.20
Chromosomes/genetic or congenital diseases	7	17.10
Metabolic disorders	9	21.90
Nervous system disorders	3	7.30
Immune system disorders	5	12.20

Health-related stigma

Overall, 75% of parents believed that a rare disease is often accompanied by a strong perception of stigma towards their child. Nearly half of parents (48.8%) believed that their child was treated differently due to their condition. Thirty-nine per cent strongly agreed that people had preconceived ideas about their child's condition, and 34.1% believed that their children had to work harder to prove themselves because of their health condition. This perception of stigmatisation was not shared by all parents, with 24.2% either neutral or disagreeing that chronic conditions attach a stigma or label to their child. No significant associations were found with stigmatisation and gender ($\chi^2(4) = 8.67$, $p = .07$) or age group ($\chi^2(4) = 3.78$, $p = .44$).

Bullying victimisation

Almost half (46.4%) of parents reported that their child had been bullied, with 24.4% of parents reporting that their children had experienced three or more instances of bullying in the last school term (see Table 2). Of the parents who reported their child being bullied in the last school term, 31.7% reported that their child were verbally abused by being

Table 2. Frequency of bullying victimisation in the last school term.

Form of victimisation	Never		Once or twice		Three or more times		I don't know	
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%
Victim of bullying	20	48.7	9	22.0	10	24.4	2	4.9
Called mean names	23	56.1	6	14.6	7	17.1	5	12.2
Left out (social exclusion)	16	39.0	14	34.1	7	17.1	4	9.8
Avoided child	25	61.0	8	19.5	5	12.2	3	7.3
Physical aggression	28	68.3	7	17.1	4	9.8	2	4.9
Cyberbullied	34	83.0	2	5.0	1	2.4	3	7.3

called mean names, 51.2% were socially excluded or left out, 31.7% were avoided, 26.9% experienced physical aggression and 7.4% had been cyberbullied. In addition, 43.0% of parents believed that their child's bullying experiences were due to their child's chronic condition, 32.7% reported their children were stressed because they had been unfairly treated or picked on by a teacher or school staff member, and 41.5% believed that teachers did little or nothing to stop bullying. There were no significant associations between bullying and gender ($\chi^2(3) = 1.78, p = .62$) or age group of the child ($\chi^2(3) = 1.23, p = .75$).

Social competence

In general, the majority of the sample demonstrated high sensory abilities and low to moderate self-care abilities (Table 3). Over half (60.9%) of parents reported their child demonstrated high levels of receptive language comprehension, and 75.7% showed high ability with their expressive language capacities.

Regarding the social impact in the school setting, 26.8% of parents reported children missing out on sports, and 26.9% reported them being unable to participate in extra-curriculum activities. Less than one-fifth (14.6%) of parents reported their children missing out on camps, and 19.5% were unable to participate in voluntary activities at school. More than three-quarters of parents (75.6%) reported that classmates of children with rare diseases did not understand their child's health condition, with 56.7% reporting that their teachers did not understand as well. While 90.5% reported that the school adequately catered for their child's mobility needs, 70.1% expressed concerns regarding their child's ability to ask for assistance or support.

Mental health difficulties

Overall, 43.9% of parents indicated their child had mental health difficulties, with at least 73.2% of these children having had these difficulties for over a year. There were significant differences between primary school (6–10 years) and high school students (11–17 years) on the prosocial behaviours ($MW-U = 162.00, z = 3.05, p = .002$); high school

Table 3. Descriptive statistics for social competence indicators.

Overall competence	Low ability		Moderate ability		High ability	
	<i>N</i>	%	<i>N</i>	%	<i>N</i>	%
Additional handicaps						
Vision	–	–	3	7.3	38	92.7
Hearing	–	–	3	7.3	38	92.7
Epilepsy	2	4.9	1	2.4	35	85.3
Communication skills						
Receptive language comprehension	7	17.1	8	19.5	25	60.9
Communication speech	5	12.2	5	12.2	31	75.7
Self-care						
Eating	5	12.2	9	21.9	26	63.4
Personal needs	9	21.9	10	24	21	51.2
Mobility						
Walking	1	2.4	5	12.2	25	60.9
Using wheelchair	–	–	1	2.5	3	7.5
Social events	3	7.3	5	12.2	26	63.4

student ($M = 7.30$, $SD = 1.84$) had higher levels of prosocial behaviours than primary school children ($M = 6.85$, $SD = 2.07$). There were also significant differences between male and female children with rare disease conditions on conduct problems ($MW-U = 270.50$, $z = 2.23$, $p = .026$), with males ($M = 2.10$, $SD = 0.60$) showing lower levels of conduct problems than females ($M = 2.70$, $SD = 0.53$).

The total difficulties score as well as each of the SDQ subscale mean scores for the current sample were compared to Australian parents' normative data from Mellor (2005) (see Table 4). An overall total difficulty score of 22.9 ($SD = 6.7$) suggests that the total score for this sample with a rare disease was over two SDs higher than Australian normative data. There were statistically significant differences between the rare disease sample and Australian normative data on all subscales, with children with rare diseases showing poorer outcomes on all scales. Effect sizes were predominantly large (see Table 4).

Correlational analysis revealed that across the data, there were significant associations between hyperactive and prosocial behaviours ($r = -.41$, $p = .01$), emotional and conduct measures ($r = .43$, $p = .01$) and between conduct and prosocial behaviours ($r = -.56$, $p < .01$).

Primary school children showed significant associations between hyperactive measures and prosocial behaviours ($r = -.56$, $p = .02$) and emotional and conduct problems ($r = .73$, $p < .01$). Among high school students, conduct and prosocial behaviours were significantly associated ($r = -.72$, $p < .01$). There were also significant associations between the emotional and peer measures ($r = .57$, $p = .01$) and conduct and prosocial behaviours ($r = -.82$, $p < .01$) for females, with no significant correlations evident between the SDQ subscale scores for males.

Bullying, stigma and mental health difficulties

Bullying victimisation was significantly associated with children's emotional symptoms ($r = .53$, $p < .001$) and peer problems ($r = .34$, $p = .03$; *nb.* peer problems include an item regarding bullying victimisation). Victimization was not significantly associated with conduct problems ($r = .12$, $p = .45$), hyperactivity ($r = .10$, $p = .55$), or prosociality ($r = .19$, $p = .25$). Stigma was also significantly associated with peer problems ($r = .47$, p

Table 4. SDQ subscales mean and SD scores for sample and Australian normative data.

Strengths & difficulties subscales	Sample Mean (SD)	Australian norm (N = 910) Mean (SD)	Possible range	Cut-off score	Test statistic, df and <i>p</i> -value	Cohen's effect size (<i>d</i>) [95% CI]
Hyperactive measure	4.7 (2.8)	3.1 (2.4)	0–10	≥7	$t(42) = 3.60$, $p < .05^{**}$	0.62 [0.35, 0.98]
Emotional problems	4.2 (2.6)	2.1 (2.0)	0–10	≥5	$t(42) = 5.10$, $p < .05^{**}$	0.63 [0.39, 1.02]
Peer problem	4.7 (1.9)	1.6 (1.9)	0–10	≥4	$t(43) = 10.22$, $p < .05^{**}$	1.63 [1.31, 1.95]
Conduct problems	2.4 (2.3)	1.5 (1.6)	0–10	≥4	$t(41) = 2.48$, $p < .05^{**}$	0.45 [0.24, 0.86]
Prosocial behaviours	7.1 (2.1)	8.3 (1.7)	0–10	≤4	$t(42) = -3.61$, $p < .05^{**}$	-0.63 [-1.01, -0.38]
Total difficulties score	22.9 (6.7)	8.2 (6.1)	0.40	≥17	$t(43) = 13.79$, $p < .05^{**}$	2.29 [2.07, 2.73]

Notes: Unequal variance assumed. ******Significant at the 0.01 level (2-tailed).

= .002). Stigmatisation was not significantly associated with hyperactivity ($r = .26, p = .10$) or prosociality ($r = -.22, p = .16$) with conduct problems ($r = .12, p = .45$). A trend toward significance was observed for emotional problems ($r = .31, p = .05$) and conduct problems ($r = .29, p = .06$). Bullying and stigmatisation were not, however, significantly correlated with one another ($r = .12, p = .47$), suggesting they are discrete and distinct processes in the lives of children with rare diseases.

Common complaints from teachers

As part of the SDQ, parents reported that 60% of complaints they received from teachers were related to their child's poor concentration or being easily distracted. Thirty-eight per cent of these complaints had to do with children acting without thinking, frequently butting in, not waiting for their turn, fidgeting and being restless and/or overactive (see Figure 1).

Discussion

The current study was aimed at providing insights into the parents' perspective of the impact of a rare disease on the school-related experiences and mental health of primary and high school children attending mainstream schools in Western Australia. Parents in our study reported that their children with a rare disease experienced elevated levels of stigma, bullying, mental health difficulties, and a lack of understanding by their peers and teachers.

In the current study, parents perceived psychological strains for their children including health-related stigma and bullying behaviours. It is evident from the study that the diagnosis of a rare disease can result in children and adolescents experiencing stigma and being treated differently. The majority of parents (75%) reported some concerns related to health-related stigma about their child's condition. The observed finding may be as a result of the discrimination, devaluation and social exclusion that is likely to be experienced by children considered not to be 'normal' by their peers (Link and Phelan 2006). This finding is consistent with the review of von der Lippe, Diesen, and

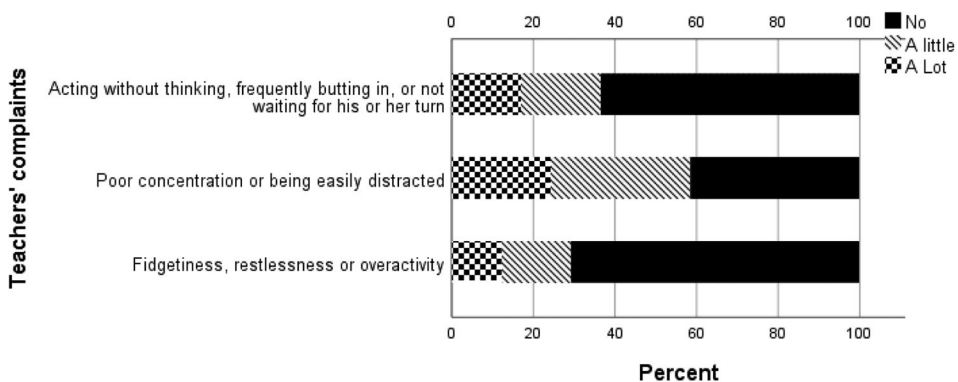


Figure 1. Distribution of common complaints from teachers of children with rare disease.

Feragen (2017) where stigma was identified as an important social consequence of having a rare disease.

Nearly half (46.4%) of the parents reported at least one instance of bullying victimisation among their child or adolescent in school. Our findings are congruent with other studies which indicated that children and adolescents with chronic/rare conditions are more likely than their healthy peers to be victims of bullying, mainly because of significant differences in their appearance or behaviour (Fong, Katelaris, and Wainstein 2018; Kavanagh et al. 2018). This percentage (46.4%) is higher than the meta-analytically defined prevalence estimate of 36% (Modecki et al. 2014), but very similar to the findings of Su (2012) in which 49.7% of high school students reported instances of bullying due to their rare disease. The inclusion of rare disease awareness education in bullying interventions may be appropriate in dealing with bullying among children with a rare disease. As bullying is also a relationship problem, Pepler (2006) suggests the use of 'social architecture' model whereby teachers and school officers restructure the social context of peer groups to prevent negative consequences of bullying. Supporting the inclusion of children with rare diseases in school activities is also essential in preventing bullying victimisation.

With regard to their child's social competence, parents reported high sensory (vision and hearing) abilities, but low to moderate self-care competence in relation to social activities and peer relations. The high scores on sensory abilities are perhaps an area that should be focussed on when developing strength-based school interventions for children and adolescents with rare diseases. Parents also reported their children missing out on sports and unable to participate in extra-curriculum activities. Given the impact of some rare diseases on the physical ability of children (e.g. mobility), it makes sense that children with a rare disease experience difficulties participating in school activities such as sport, extra-curriculum and other voluntary activities. This finding may be explained in the work of Hendriksz et al. (2014) in which restriction in mobility among children and adolescents with a rare syndrome (Morquio A syndrome) was reported to reduce mobility, self-care and usual activities. Given the positive effect of sports on the psychological well-being of children (Vella et al. 2015), it is imperative to ascertain alternative means of getting children and adolescents with a rare disease involved in tailored sports/physical and extra-curriculum activities by engaging with students, parents and healthcare providers.

Another significant finding from the current study is that the majority of classmates (75.6%) and more than half of the teachers (53.7%) did not understand the child's rare health condition. This may be as a result of teachers' lack of knowledge on the child's rare disease or lack of partnership with parents and healthcare providers (Irwin and Elam 2011). This finding contradicts the previous work of Zurynski, Deverell, et al. (2017) where teachers were identified as being instrumental in the diagnosis of rare disease among children. It also raises a very important question on whether children want to disclose their health conditions. Peers and the teachers' lack of understanding may be partly due to an adolescent's reluctance to disclose their health condition to their peers for fear of being labelled or stigmatised (Kaushansky et al. 2017). In addition, parents reported receipt of various complaints from their child's teachers regarding their child's behaviour in school. Of these, more than one-third were related to children acting without thinking, frequently butting in, not waiting for their turn, fidgeting, being restless and/or overactive. It may be that teachers' lack of understanding of the child's

condition may have contributed to these observations and complaints. However, given the appropriate education and support on rare diseases, teachers may become a great source of support for children with rare diseases at school.

Prosocial behaviour scores for high school students were significantly higher compared to primary school students in this study. This observation may be due to self-awareness associated with adolescence and the importance of friendship and spending time with peers away from parents (Parkyn and Coveney 2013; Helms, Dellon, and Prinstein 2014). It could also be explained in terms of the adolescents' ability to develop coping skills after years of living with a rare disease. In addition, an overall strong positive correlation between emotional and conduct measures was observed. That is, children with high emotional difficulties are likely to have conduct problems. Thus, by managing emotional difficulties, conduct problems can also be de-escalated. This finding is relevant for teachers in identifying and managing behaviours in class. We also found less conduct problems among male children than female children. This finding contradicts that of Gutman et al. (2018) in which male children aged 3–11 in the United Kingdom scored high in conduct problems using the SDQ. This difference may be partly due to the small sample size in our study and/or the uniqueness of children with rare diseases. However, the conduct problems observed in our study are not very concerning as they are below the cut-off point score (≥ 4).

Bullying and stigmatisation were associated with emotional symptoms and peer problems in children with a rare disease. It was noted that stigma was more strongly associated with peer problems than bullying, given that the SDQ Peer Problem scale includes an item on bullying. Stigma may be more common than overt bullying, and a measure of stigma may pick up on more subtle processes of peer exclusion and ostracisation than does assessment of bullying.

Finally, the finding of elevated mental health difficulties in this study supports the notion that children with rare diseases are at greater risk of mental health difficulties. The scores on the SDQ in this sample were well above Australian norms (Mellor 2005), and they displayed poorer prosocial behaviours. Our finding is similar to those reported by Cole et al. (2013) where higher levels of emotional difficulties were recorded among children with a specific rare disease (Chronic Granulomatous Disease).

Limitations

This study has limitations. First, our data relied on parent proxy-report rather than child-reports. It is argued that bullying among children can be underreported in studies using proxy reports, mainly because bullying prevalence will be dependent upon the parents' knowledge of whether their child was bullied or not, and the parents' interpretation of the situation (Nordhagen et al. 2005). A second limitation is the small heterogeneous sample in terms of diagnosis, severity and co-morbidity. Thirdly, the sample was a self-selected sample and may not be a representation of the wider population of children and adolescents with rare diseases. Finally, teachers' perspective was not included in the current study. Future research with larger and more representative samples is needed to identify children and adolescents' perspectives of rare diseases and their impact on their school life. Future research should also capture the voice and perceptions of students with rare diseases. In addition, further research is needed to identify the types of training

or interventions needed to accommodate the needs of children and adolescents with rare diseases in schools from the perspective of teachers.

Implications for practice and policies

The findings of this study highlight the role of the social ecology of school settings on the mental health and social adjustment of children with chronic physical health conditions (Runions et al. 2020). As such, the findings have important implications for educators and school administrators. School officials including teachers need to be aware of the impact of rare diseases on a child's school experience, and in particular, their psychosocial experiences. Bullying and stigmatisation need to be topics of consideration when teaching a child with a rare disease and targeted bullying prevention policies and practices, with a clear evidence base, in schools. Issues of victimisation, harassment, or discrimination based on medical health or special needs are unacceptable forms of behaviour. From that point of view, training for educators to understand children's educational and health needs while in school is imperative. It is the responsibility of school administrators to achieve a more cohesive school environment and appropriate activities for facilitating children's inclusion and participation in school-related activities. Establishing coordinated communication with parents, school staff and healthcare professionals is another strategy to help teachers understand and recognise potential medical issues in the child, as well as to facilitate peer support that promotes social and mental well-being of children with rare diseases.

Classroom teachers should be aware of overt and covert types of bullying victimisation and stigmatisation and use positive teacher–student relationships to manage them (Irwin and Elam 2011; Pepler 2006). Additionally, teachers should foster an inclusive school/classroom environment where children with rare diseases feel welcomed and accepted.

Conclusion

Living with a rare disease can have a significant impact on school experiences and mental health of children and adolescents. Parents of children and adolescents attending mainstream schools in Western Australia have reported stigmatisation, bullying, behavioural and emotional difficulties. The rate of bullying perceived by parents was higher than the Australian norm. This is concerning as bullying behaviours have a negative impact on the school experiences of school-age children. A lack of educational support and understanding of the child's rare disease can restrict a child's social competence, development and welfare. Targeted school-based interventions for children with rare diseases are needed to prevent the negative psychosocial outcomes among children with rare diseases.

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