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Parents' experiences of children with a rare disease attending a mainstream school: Australia

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Title: Parents' experiences of children with a rare disease attending a mainstream school: Australia

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Empirical Study: Abstract
Purpose: To explore the perceptions of parents who had a child or adolescent (6-18 years) diagnosed with a rare disease who attended a mainstream school in Western Australia.
Design and methods: A cross-sectional online survey was conducted with 41 parents of children with a rare disease. Here we report the findings of 14 open-ended questions on their experience of illness-related factors and impact on school-related social activities, such as sports, school camps and leadership roles whilst their child with a rare disease attended a mainstream school in Australia. Responses were analysed using an inductive thematic content approach.
Results: We identified three themes (resources, experiences and needs), seven categories (illness, support, knowledge, acceptance, isolation, activities of daily living and adjunctive therapy) and 24 codes from the parents' responses describing the experiences of their child at school. Parents want the government and educational systems to provide the necessary funding and resources to reflect an inclusive curricula and supportive environment that can meet the learning needs of children with a rare disease at a mainstream school.
Conclusions: Further research, policy development and interventions are needed to explore how schools can meet the diverse psychosocial physical and emotional needs of children diagnosed with a rare disease who attend a mainstream school in Australia.
Practice Implications: A child needs to be viewed from a holistic ecological viewpoint; future research with larger representative samples to explore rare disease experiences and a critical review of existing legislation, interventions and initiatives is required.

Keywords: Rare Diseases, Children, Mental Health, Parent-Report, Australia, Education

Introduction

To date, there are about 296 definitions of rare diseases (RDs) (Richter et al., 2015) and 7000 different RDs worldwide (Rosselló et al., 2018). Cutting across these definitions is the reality that RDs are chronic, severe and/or progressive and can cause various degrees of sensory, motor, physical and intellectual disability (Rosselló et al., 2018). Fifty percent of RDs have their onset within the first year of life, with 10% an onset between 1-5 years of age and 12% presenting between 5-15 years of age (Rosselló et al., 2018). The clinical expression and presentation of RDs varies widely, dependent on type and severity with many demonstrating numerous and prominent physical symptoms whereas others have mild manifestations (Joldic et al., 2019; Kepreotes, 2014). The Australian government define a RD as a disorder that affects less than 5 in 10,000 people, however, many RDs are often associated with other behavioural and/or mental health disorders; for example, 30% of children with Fragile X syndrome, also have autism spectrum disorder (Australian Government, 2020; De Rubeis, 2018). Attention problems such as attention-deficit/hyperactivity disorder, autism, visuospatial and hearing difficulties, language, memory, and executive dysfunction, physical abnormalities and neurocognitive symptoms are common and place children with a RD at a higher risk for adverse social experiences and bullying than their healthy peers (Moffat et al., 2019). It is estimated that 5-6% of the general population live with RDs globally, yet the reported incidence of RDs has been ambiguous due to the rareness of the diseases and the relatively small number of people affected by specific RDs (Jackson, 2017; Rosselló et al., 2018).

Globally, the survival rate for children who have a RD is increasing due to advances in medical science and improved understanding of genetic disorders (Jackson, 2017). Despite the advancement in medical technology, RDs continue to negatively affect children and their significant others (Adama et al., 2021). The physical, psychological, social and economic impact of RDs on individuals and their families suggests a need to implement a multisystem inter and intra disciplinary coordinated approach that includes teaching, health, care delivery and health promotion within the community, school and hospital context (Anderson et al., 2013; Germeni et al., 2018; Kepreotes, 2014; Nabbout et al., 2019; Ypinazar, 2015). These challenges are even greater for parents who have limited resources or do not meet the functional criteria for financial and educational support (Australian Research Alliance for Children and Youth, 2015).

Most research on RDs have focussed on disease diagnosis, classification and treatment (Aflaki et al., 2017; Cacioppo et al., 2016; Hirsch et al., 2020; Ronicke et al., 2019). Although many of the needs of people living with RDs may not be met by physicians or specialists, people living with RDs seem to use healthcare services more than the general population (Molster et al., 2016). In a recent survey of paediatricians in Australia, frustrations and lack of knowledge to support patients with RDs and their families was evident as RD management was not part of their university or fellowship training (Zurynski, Gonzalez, et al., 2017). Without adequate training of doctors, nurse practitioners and other disciplines to manage RDs, children are likely to be in school without appropriate individualised management plans, which will in turn influence their school experience.

Relatively little research has focused on the lived experiences of the people affected by RDs. Studies describe parents' perceptions of the psychological impact including stigmatisation, bullying, social competence, chronicity, distress, social impairment and burden to others of children with RDs attending a mainstream school (Adama et al., 2021), parental impact of a RD diagnosis (Kepreotes, 2014) and a critical review of the literature to classify, compare and summarise the quality of life of three RDs (Duchenne muscular dystrophy, achondroplasia and osteogenesis imperfecta) from a patient, caregiver and sibling lens (Dogba et al., 2014). Using quantitative data from the sample described here, we showed that parents' experiences on their child's schooling included stigmatisation (76%), bullying (47%) and mental health difficulties (44%). Bullying at school included

name calling (51.2%), exclusion (31.7%), avoidance (26.9%) and physical aggression (7.4%), and these were higher than the norm (Adama et al., 2021). Similarly, social exclusion, avoidance, behavioural and emotional difficulties in children with RDs were further reported by parents (Dogba et al., 2014; Kepreotes, 2014). These studies highlighted a need for greater efforts to meet the unique psychological needs of children diagnosed with a RD who attend mainstream schools.

Despite a plethora of reviews on children with a chronic illness (Leroy et al., 2017; Lum et al., 2017; Runions et al., 2020; Uhm et al., 2020) and exclusionary school practices (Connolly, 2017; Lacono et al., 2019), there are only two recent reviews undertaken that explore peer (Edwards et al., 2019) and medical staff (Dogba et al., 2014) perceptions on the impact of a RD within a medical and school environment. Edwards et al. (2019) reviewed 10 articles on peer engagement with children who had a disability using the Koster et al. (2009) framework that included three social inclusion components being positive peer interaction, peer acceptance and friendship. They reported that students without special needs avoided interacting and were less accepting and willing to befriend a student with a physical impairment in the classroom. This was influenced by three socio-ecological levels being individual, interpersonal, and contextual which included the peer's gender, age, knowledge and previous experience of disability, whether they shared similar hobbies, ability to communicate with the child, social pressure including their role in the classroom and whether they perceived their safety was at risk. Edward et al., (2019) further conveyed that the interventions were resource intensive and required implementation by researchers and teaching assistants outside of the classroom and recommended that interventions need to be included and implemented as part of the school curricula to promote inclusivity for children with RDs.

School inclusive initiatives and practices for children with special needs have been reported in the literature where common findings were reported. These included the need for an interdisciplinary and transdisciplinary approach, further education for teachers, management and leadership and an awareness that inclusive school-based interventions are effective in facilitating a positive impact on a child's learning and well-being (Gavish, 2017; Government of Western Australia Child and Adolescent Health Services, 2019; Rosselló et al., 2018; Spaniol et al., 2018; Sutton et al., 2019; Tones et al., 2017; Wu et al., 2019; Yamanashi, 2017). In a New Zealand study patients with RDs reported a delay in diagnosis and a lack of support, pain, fatigue, reduced vision, fear, uncertainty, loneliness and isolation with a need to build self-resilience (Tai et al., 2017). Although this study explored one specific RD, Behcet's Syndrome, the respondents' experiences were congruent across other RD studies irrespective of RD typology.

In a study among children with RDs in Australia, similar issues regarding diagnosis delay, lack of support and information were raised by children and their families (Zurynski, Gonzalez, et al., 2017). Using focus groups and in-depth interviews, Pelentsov, Fielder, and Esterman (2016) analysed data on the experiences and support needs of 23 South Australian parents whose children were diagnosed with a RD. They showed that parents of children with RDs "felt boxed-in outside the box" dealing with the "practicalities of care" and having to deal with the "various relational impacts" that arise as a result of having a child with a RD (Pelentsov et al., 2016). Similar findings were previously reported by Anderson et al (2013). From this body of research, it has been established that having a RD or a child with a RD is associated with feelings of frustration in obtaining an accurate diagnosis, lack of support from the healthcare service providers and peers, lack of understanding/knowledge and financial support that increases mental health issues for the child and/or family (Adama et al., 2021; Kepreotes, 2014).

To date, very little research has examined the school experiences of children with RDs from their parent's perspective. The majority of the literature reports on the parents' experiences of a child with RDs within the healthcare system, their daily routine and general interactions with other service

providers (Pelentsov et al., 2016; Tai et al., 2017; Zurynski, Deverell, et al., 2017). Schools provide a setting for children with chronic physical health conditions that may exacerbate or alleviate challenges to wellbeing and mental health (Runions et al., 2020). Relationships with the teacher, peers, and between teachers and parents may all impinge on the quality of life of children with chronic conditions, via processes of stigmatisation, disruption of relationship formation due to illness and treatment, and ignorance regarding the condition and how to support the child (Runions et al., 2020). Therefore, this study is aimed at exploring the school experiences of parents of school-aged children with a RD attending mainstream school in Western Australia.

METHODS

Design

This qualitative study explored the experiences of parents who had a child or adolescent (6-18 years) diagnosed with a RD who attended a mainstream school in Western Australia. This study was conducted as part of a larger online survey conducted on the wellbeing and school experiences of children and adolescents with a range of chronic conditions, namely type 1 diabetes, hearing loss, cystic fibrosis and RDs, as reported by parents. The larger survey includes four validated measures addressing parental perceptions on the level of stigma their child experienced, social-emotional strengths and difficulties, bullying and social competence respectively (for details see Adama et al., 2021). This paper presents analyses based on 14 open-ended questions that explored condition-specific versus condition-general and illness-related factors related to their child's experiences at their mainstream school in Australia.

Participants

The study included a convenience sample of 41 self-identified mothers of a child or adolescent (6-18 years) diagnosed with a RD who attended a mainstream school. We relied on parent report of their child having an RD. Inclusion criterion included parents with a child diagnosed with a RD attending a mainstream school, capacity to respond in English, ability to complete the questionnaire and voluntary informed signed consent.

Data Collection

The online survey was accessed via a web link during March and August 2016 and took 20-30 minutes to complete. Participants were required to complete the survey in one sitting. Eligible parents received detailed information about the study before deciding whether to participate and needed to complete the consent form before proceeding onto the survey. Recruitment pamphlets and posters were placed at the Genetic Services Clinics at Princess Margaret Hospital (PMH) in Perth, Western Australia (WA) and advertised through the Genetic and Rare Disease Network, Rare Voices WA, Genetic Services WA, Office of Population Health Genomics, Children Tumour Foundation, ARCAN, Cleftpals, Charge syndrome association, VCFS 22q11 Foundation, Neurofibromatosis Association WA Inc., Short Statured People of Australia Inc. (Achondroplasia), Muscular Dystrophy WA, Duchenne Foundation Australia, Telethon Kids Institute, newsletters, social media and websites which contained the link to the study participant information form and survey. The WA Department of Education's School of Special Educational Needs: Medical & Mental Health (SSEN: MMH) assisted with recruitment. Ethics approval was granted by the Child and Adolescent Health Human Research Ethics Committee.

Open-ended questions

The 14 open-ended questions were developed in consultation with clinical staff, parents and support groups to explore illness-related factors specific to RDs and impact on school-related social activities, such as sports, school camps and leadership roles (Table 1). Demographic details were collected on gender, postal code, place of birth, year level at school, ethnicity, and combined family income.

Table 1: Open-Ended Questions

1.	Do you feel your school adequately caters for your child's personal care needs, please explain?
2.	Does your child's school adequately cater for their mobility needs, please explain?
3.	Does your child feel that their classmates understand their condition, please explain?
4.	Does your child feel that their teacher understands their conditions, please explain?
5.	Has your child ever found it difficult to tell their teacher or other staff at school if they need support for their condition, please explain?
6.	Does your child feel that there is someone who can help them if they need support at school, please explain?
7.	Thinking back to the last school year, excluding school holidays, how many days was your child absent from school, specifically because of their chronic condition, which includes hospitalisation, appointments, treatment or sick days, or for other reasons?
8.	Does your child's condition limit them in participating in voluntary school activities such as leadership, volunteering for an activity or contributing to class discussions, please explain?
9.	It is known that some children may miss out on sports at school because of their chronic condition. How often does this happen to your child and why has this happened?
10.	It is known that some children may miss out on school camps because of their chronic condition. How often does this happen to your child and why has this happened?
11.	It is known that some children may miss out on school excursions because of their chronic condition. How often does this happen to your child and why has this happened?
12.	If your child is unable to attend a sporting event, camp or excursions, what alternatives are offered as compensatory learning?
13.	Because of their chronic condition, how often has your child been unwilling or unable to participate in extracurricular activities such as music, arts or drama activities?
14.	Do you feel that there is enough assistance in school for your child with a chronic condition, please tell us more if you would like to?

Data analysis

We used inductive thematic content analysis (Braun & Clarke, 2006) to analyse open-ended responses. Data on the phenomenon of the research question were underlined (findings), coded (in Nvivo coding) and grouped into smaller or larger categories and themes based on similarity of meaning by three independent coders (Attride-Stirling, 2001; Thomas, 2006). The researchers moved between the data and reviewed the codes, categories and themes multiple times in a repetitive cyclic process iteratively until no new themes or categories were evident or the researchers felt the themes portrayed the meaning and significance of the text.

Results

Forty-one 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). Almost one in three participants had a RD categorised under the musculoskeletal category (n=12, 30%). Thirty-eight children required the aid of glasses to achieve normal vision (n=38, 93%), 39 (95%) had a degree of deafness, 6 (15%) used a wheelchair and 9 (22%) were dependent on others for activities of daily living. The average weekly family income was $1,995 with the majority of families earning $1500 - $2999 per week (Table 2) which is lower than the reported mean weekly gross household income for 2016 (Australian Bureau of Statistics, 2017).

Table 2: Parent and Child Demographics (N = 41).

Variable	**Child number (n, %)**

Rare Illness Category	
Musculoskeletal	(12, 30%)
Haematology	(5, 12%)
Genetic	(7, 17%)
Metabolic	(9, 22%)
Neurology	(3, 7%)
Immunological	(5, 12%)
Child's Gender	
Female	(22, 54%)
Age (years)	
Primary (6-10)	18 (44%),
High School (11-17)	23 (57%)
Family Income per Week	
$1-$1499	(8, 20%)
$1500-$2999	(17, 41%)
$3000 and more	(8, 20%)
Vision	
Wears Glasses	(38, 93%)
Partial Sight	(3, 7%)
Hearing	
Deafness in One Ear	(39, 95%)
Partial	(2, 5%)
Seizures	
None	(35, 85%)
Controlled	(1, 2%)
Uncontrolled	(2, 5%)
Self-Care	
Independent	(21, 52%)
Needs Help	(10, 24%)
Dependent	(9, 22%)
Mobility	
Walks Un-aided	(30, 73%)
Wheelchair Use	(6, 15%)

Open Ended Questions

The mothers' responses from the 14 open-ended questions were synthesised into 24 codes across seven categories (illness, support, knowledge, acceptance, isolation, activities of daily living, and adjunctive therapy) that were then synthesized into three overarching themes (resources, experiences, and needs) related to the child's psychosocial, physical and emotional wellbeing (Table 3). Some examples of responses are included in Table 3.

Table 3: Parents' Experiences as Child Proxies

Theme	Category	Codes	Representative Quotes
Resources	Illness	Prognosis	*"At present no treatment, unknown"*
		Diagnosis	*"My daughter was originally diagnosed with Spastic Diplegia CP"*
		Mental Health Comorbidity	"*Stated Other because health professional hasn't told me but, as Mum, I see separation anxiety, some OCD, some depression"*
	Support	Camps	*"School camp this year did not provide suitable food, we had to provide all meals from home"*
		Sports	*"Sports conducted off site and he is too slow getting over there and cannot walk/run safely"*
		School	*"School only just created an individual education plan to cover her vision and hearing issues in the last month after being at the school for 18 months"*
		Hospital	*"Hospital never involved as they didn't see him as 'at risk'. No other services available unless we go private, which is too hard when we have to maintain work commitments mon-fri and don't reside near PMH"*
		Home	*"Could be some extra help for at home"*
		Classroom	*"The classroom layout is designed with her in mind"*
	Knowledge	Teacher	*"Teachers are aware of allergies but it is often difficult for them to understand that my daughter can suffer allergic responses without coming into contact with an allergen"*
		Parent	*"Unfortunately, the child needs to fit into the strict criteria from the Education Department, and with a rare disease, they may need the extra support but there may not be provision in the "rules" for extra support because the child does not have a diagnosis recognised by the Ed dept"*
		Public	*"As my child has a rare condition there is not much public awareness"*
Experiences	Acceptance	Communication	*"He doesn't want to talk about it at all, he doesn't feel comfortable talking to a teacher and will not tell them anything"*
		Understanding	*"The kids don't 'understand' her condition but they do understand that she is just another kid like"*
		Normal	*"My son is treated like any child without a rare disease, he is not looked at differently"*
	Isolation	Exclusion	*"Missed graduation camp due to chemo and excursions due to treatment or due to them being physical activities he could not participate in (ice skating etc) excluded".*
		Abnormal	*"Our son condition and medications means his body cannot regulate his body temperature so on hot days it is too much for him and we ask that he sits out and in the cool, heat is also a trigger for seizures"*

		Bullying	*"Discrimination against his height, most kids tease him mercilessly"*
Needs	Activities of Daily Living	Mobility	*"My daughter uses a mixture of quadsticks (within the classroom/confined spaces), a walker (medium distances <200m) and wheelchair (>200m)"*
		Medication	*"Treatment for seizures, including 5 different medications"*
		Nutrition	*"Phenylalanine free formula given 3x daily to supplement diet"*
	Adjunctive Therapy	Therapy	*"Ongoing maintenance clinics at PMH, including Neurology, Dental, Orthopaedic, General Paeds, yearly hearing and eye checks, Eye and hearing tests annually. Blood tests annually"*
		Doctor's Appointments	*"3 monthly scoliosis review and brace adjustment, 6 monthly epilepsy review, yearly ophthalmology review, yearly brain and spine MRI"*
		Hospital Admissions	*"16 fort nightly rounds of chemotherapy with an average of 5 nights inpatient treatment per fortnight"*

Resources

The theme *resources* included the categories *illness, support* and *knowledge* and contained 12 codes and 159 findings that synergistically influenced the parents' perception of their child's psychosocial physical and emotional wellbeing as a student attending a mainstream school (Table 3).

Illness

The resources available to the child, mothers and school appeared to be influenced by whether a definitive *diagnosis* and/or *prognosis* had been made which then influenced the child's eligibility for government funded support to meet the learning needs for that child. Five mothers reported that their child was labelled with a title which did not include the set criteria for government funded support; ten mothers stated their child had a mental health problem either diagnosed (n=3), still being diagnosed (n=3) or where educational and medical staff were in discourse over a psychiatric diagnosis (n=4). Sixteen mothers stated that if their child had a definitive RD and mental health diagnosis with a set prognosis, this helped them feel better in relation to their child's mental health and wellbeing at school.

Support

The category *support* included the codes *school, classroom, sports, camps, hospital* and *home* environment that were synergistically interconnected and influenced by whether the child had an illness that was government funded or not (Table 3). One mother stated that "support has never been given" within the hospital, home or school setting and the option for private treatment or tuition was too expensive so mothers relied on charitable organisations or the family's resources to facilitate their child's learning. Twenty-seven mothers stated that the schools "did provide for their child's learning" and that "over time support increased". The support offered to some children to participate in usual school activities (sports, camps) were reported as positive experiences when "resources were available" and/or "modifications to the building, curricula or classroom" setting had occurred. Mothers reported negative experiences such as "being overlooked" (n=2), "missing out" on camp/sports activities (n=26) or "no support offered by the school" (n=11). Mothers reported on using innovative strategies to protect or facilitate their child's involvement by being "parent helpers" (n=1), "providing food" (n=1) or "planning an alternative excursion" (n=2).

Knowledge

The category *knowledge* included the *parents', teachers' and public* (governmental) understanding and awareness of rare medical illnesses in children (Table 3). Seven parents stated that if the "school valued" and "listened to the parents' expertise on their child's needs" and had an "increased awareness on rare medical illnesses" the likelihood of increased satisfaction and mental health and wellbeing for these children could occur. Twenty-seven mothers stated that the schools "catered in some degree for their child's learning"; however, 22 mothers also suggested that the "schools were not fully equipped to provide a positive learning experience for their child" whether due to "lack of funding", "knowledge" or "understanding".

Experiences

The theme *experiences* included the categories *acceptance* and *isolation* and contained six codes and 88 findings (Table 3).

Acceptance

The category *acceptance* included the codes *communication, understanding and normal*. Communication was reported by 15 mothers as an important factor that dictated whether the child "was included" (n=4), "had friends" (n=3) and "felt normal" (n=13). Limited communication between the child, other children and teachers were reported by mothers as being due to the child's speech, cognition, confidence, type of illness or where communication with the school was disjointed. Five

mothers stated that their child's understanding of the medical illness appeared to influence how they interacted and communicated with their peers. One mother relayed that other children accepted her child despite not understanding the illness and 13 mothers stated their child "just wanted to be treated like everyone else". Normal included usual behaviours and ailments children with or without a RD could experience such as ear infections, viral illnesses and anxiety. Being "treated as normal" "with specialised facilities available to assist children to participate in everyday school activities", "to feel included", "understood" and "listened to" were common findings reported by mothers in this study that influenced whether they perceived their child felt accepted.

Isolation

The category *isolation* included the codes *exclusion, abnormal* and *bullying*. Exclusion was commonly reported by mothers in this study, whether due to the child excluding themselves from activities by choice (n=1), the school not enabling inclusion due to lack of support (n=13), the severity of the illness (n=3), parents selectively excluding their child from activities they could not perform (n=2) or inappropriate alternatives offered by the school (n=11). However, five mothers did state their child was included in sports and out of school activities. Here, there were many negative reports on the child's wellbeing, including "exclusion" (n=34), verbal/physical "bullying" (n=7) and feeling "abnormal" (n=11). Despite seven mothers reporting on episodes of physical and verbal bullying, only one mother stated the school was supportive when a bullying situation arose. Abnormal was associated with symptoms experienced by nine children at school and included seizures, muscle spasms and chronic pain. The mothers perceived these symptoms increased feelings of burden, stress and embarrassment for their child.

Needs

The theme *needs* included the categories *activities of daily living (ADL)* and *adjunctive therapy* and contained six codes and 112 findings (Table 3).

Activities of daily living (ADL)

The category *ADL* included the codes *mobility, medication* and *nutrition*, and considerations for the child with a RD on a daily basis. Mobility aids (n=11) and/or difficulties (n=12) with mobility (getting to and around the school) were reported by 23 mothers as an important aspect of their child's daily life. Mobility included the use of wheelchairs (n=6), a walker (n=1), quadstiks (n=1) and ankle foot orthotics (n=3). Medication administration was a common factor reported by 21 mothers as a normal part of the child's everyday life and included oral (n=6), subcutaneous (n=2), intramuscular (n=2), ventilatory (n=1) and/or infusions (n=2) administered once (n=7) or more than once a day (n=4), weekly (n=2) or as a continual therapy (n=1). Nutritional requirements were reported by 12 mothers as an activity that affected their child's health if not adhered to and included gluten free diets (n=5), low protein diets (n=4), formulae (n=2), phenylalanine free diets (n=1) and food allergies (n=1). Four mothers stated the school did not understand the significance of their child's dietary restrictions or provide appropriate dietary options.

Adjunctive therapy

The category *adjunctive therapy* included the codes *therapy, doctors' appointments* and *hospital admissions* that was influenced by diagnosis, prognosis and level of need. Therapy covered a range of out of school activities that all the mothers reported their child attended on a weekly, two weekly, monthly, six monthly or yearly basis and included speech (n=11), behavioural (n=4) and social coaching (n=1), physiotherapy (n=15), occupational therapy (n=13) and rehabilitation programs (n=1). In synergy with this, 33 mothers reported that their child attended specialist appointments which included regular renal (n=2), ear nose and throat (n=2), ophthalmology (n=3), plastics (n=3), endocrinology (n=2), orthopaedic (n=9), neurology (n=5), gastroenterology (n=2), dietetics (n=2), dental (n=2), cardiology (n=2), immunology (n=2) and/or anaesthesiology (n=1) visits with further

diagnostics and surgery including MRIs (n=2), blood screening (n=1), Botox injections (n=2), hip and orthopaedic surveillance (n=2), chemotherapy, grommets, limb salvage, skin grafts, donor allograft, muscle resection, bone fusion and/ or genitourinary surgery (n=7).

Discussion

In this study, we examined the experiences of parents as proxies for their child diagnosed with a RD who attended a mainstream school. We found a diverse range of experiences (bullying, exclusion, isolation, impaired communication, and poor support) reported by parents as proxies for their children. These experiences were influenced by the child's diagnosis, severity, degree of disability, clinical expression and support available from the school and/or government. Parents who had a child with a high degree of disability (mobility, uncontrolled seizures, required assistance and hearing or vision impairment) reported that the school was not equipped to support the child, did not value parental expertise, lacked funding, understanding or knowledge of a RD. Alternatively, parents who had a child with a lesser degree of disability (being able to walk unaided, had no seizures and were independent) reported satisfaction in the child's learning when resources or modifications to the classroom and curricula were initiated over time. The degree of disability, modification to the school, knowledge of RD, acceptance and available support influenced whether the child could participate in usual school activities (camps or join physical education classes). These findings provide preliminary evidence that may guide schools working with children with RDs and their parents in identifying higher risk profiles that may warrant early and intensive pre-school enrolment assessment and ongoing iterative intervention to mitigate negative outcomes and facilitate an inclusive equitable learning experience.

Negative experiences reported by parents in this study included exclusion, isolation, bullying and the burden to provide food, assistance and/or alternative excursions for their child whilst at school. Acceptance was influenced by how accepted, valued and included the parents' felt by the school and community, the child's RD diagnosis and severity, peer acceptance and the child's resilience. Children with RDs have reported difficulty in making and maintaining social relationships, bullying, isolation, depression, anxiety, exclusion, lack of support and show a higher prevalence of social dysfunction at schools (Adama et al., 2021; Gaintza et al., 2018). Among students with disabilities, bullying victimization ranges from between 24 to 34% (Beckman et al., 2020; Yell et al., 2016). Further understanding to explore the emotional and social burden of bullying in children with RDs from the varying viewpoints of the child, peers, parents and teachers may help highlight anti-bullying interventions for inclusive practices, coping, skill development, resilience and healthy psychosocial adjustment at school.

Similarly, parents, teachers and organisations globally have reported on a lack of support available to children with RDs at schools (Adama et al., 2021; Government of Western Australia Child and Adolescent Health Services, 2019; Lacono et al., 2019; Rosselló et al., 2018). This literature reported on a lack of diagnoses, inadequate knowledge and difficulties in managing mental and medical health conditions at school, as well as issues regarding, a lack of confidence for teachers, selective eligibility criteria for teaching support being limited to diagnosis, difficulty in implementing an inclusive curricula and limited communication with the child, family, school and multidisciplinary team (Adama et al., 2021; Government of Western Australia Child and Adolescent Health Services, 2019; Lacono et al., 2019; Rosselló et al., 2018). Within the literature an undercurrent theme is evident which underpins a disconnect between special educational needs, inclusive policy development, legislation and practice with various frameworks, initiatives and outcome measures being used that was further highlighted by parents in this study as proxies for their children. (Australian Research Alliance for Children and Youth, 2015; Edwards et al., 2019; Jackson, 2017; Lacono et al., 2019; Rosselló et al., 2018; Runions et al., 2020; Sutton et al., 2019).

Of interest, Bowles et al. (2016) reported that school-peers of children (6-8yrs) with Downs syndrome in a mainstream school enjoyed learning Lamh sign language and further understood the importance of its use with children who had a communication impairment (Bowles & Frizelle, 2016). Rathmann et al. (2018) compared student health and well-being scores with and without a disability or special educational need that attended a mainstream school or separate special school. The prevalence and likelihood of poor health and low life satisfaction scores for students who had a disability or special educational need attending a separate special school were higher compared to students attending a mainstream school (Rathmann et al., 2018).

An inclusive education includes the integration of students with and without disabilities into mainstream schools (Bates et al., 2015; Terzi, 2014). Some key areas schools need to consider in creating and maintaining an inclusive school environment for children with RDs include minimising any distress experienced by children; defining and promoting inclusive RD teaching practices; prioritising children's rights and well-being; creating school-child-peer consumer groups and acting with broad principles which would need consideration and adaptation based on local regulations, laws and resources (Australian Government, 1992, 2013; Maciver et al., 2020; Productivity Commission, 2019). Some areas the government needs to consider in creating and maintaining an inclusive school environment for children with RDs are regular internal and external auditing and accreditation of schools' inclusive RD practices; curricula and outcomes; needs based funding; professional pathways whereby teachers can undertake further RD education and the delivery of a RD inclusive curricula by a designated education professional body as directed by evidence based literature, legislation and informed service and consumer decision making (Bronfenbrenner, 1977; Hancock & Lima, 2017; Maciver et al., 2020; Roesler & Obst, 2020; Terzi, 2014).

Limitations

Some of the limitations evident in this study include a small heterogeneous and non-representative sample in terms of RD diagnosis, severity and co-morbidities. All respondents were mothers and recruitment was through an online survey where families without internet access could not participate. Additionally, we analysed responses to open ended questions and our data was limited. Focus groups or individual interviews would have provided richer and more detailed data, albeit with a greater time and logistical cost to the families.

Implications for Clinical Practice

Our findings confirm that a child with a RD needs to be viewed from a holistic ecological viewpoint taking into consideration the child's age, competency, capacity and psychosocial, emotional, cognitive, and physical, developmental level. Children with RDs and their families need transparent iterative communication, engagement and positive outcomes for the child, family, school, healthcare team, community and society as a whole. Future research with larger representative and inclusive (mothers and fathers) samples to explore how these experiences are influenced through resources, policies, guidelines, legislation, acuity, prognosis, needs, support, and RD knowledge from multiple viewpoints is required. This includes the views of the child, parent, teacher and medical team to direct evidence based contextually relevant interventions, initiatives and policy development to create an inclusive cohesive culture to support children with RDs attending a mainstream school. The government, education providers and healthcare team need to be aware of the latest literature, policies, pathways, and legislation to meet the child's and family's needs with a RD from a multidisciplinary lens to facilitate an inclusive environment and be proactive to challenge any service provider, act or agency when a child's needs are not being met.

Conclusion

Parents of children with a RD reported significant barriers in their child's education and want the government and educational system to provide the necessary funding and resources to reflect an

inclusive curricula and environment that could meet the psychosocial, emotional, physical and learning needs of children with a RD whilst attending a mainstream school. These included needs-based financial support, improved knowledge and acceptance, more effective communication pathways, promotion of mental health and wellbeing, and the need for specialised RD programs for children with ongoing vision, hearing, speech, behavioural, medical and mobility impairment. Further research, policy development and targeted interventions are needed to explore how schools can meet the diverse psychosocial physical, emotional, and learning needs of children diagnosed with RDs who attend a mainstream school.

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