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Inclusion and equity in educational services for children with rare diseases: Challenges and opportunities

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ABSTRACT

Inclusion of children with rare diseases in school poses challenges for the educational services, teachers and other school staff. This research aimed to identify these challenges based on information provided by children with rare diseases, families and school personnel.

A qualitative study was conducted using the social-critical paradigm as theoretical perspective. This study included 43 participants. Data was obtained through in-depth interviews and focus groups and analysed with discourse analysis.

A total of 10 categories were identified that influence a healthy, inclusive and equal education experience in school: Diagnosis, Official recognition, Accessibility, Absences, Coordination, Curricular adaptations, Homework, Autonomy, Personnel resources, Peer support.

The provision of appropriate education and care is a complex process influenced by the health condition of the individual child, the level of empowerment of families, the availability of resources and the commitment of the school and health care providers. The delay or lack of a clear diagnosis is among the challenges to obtaining the adaptations required.

1. Background

Rare diseases are generally chronic, progressive and severe and affect a minority of the population with varying degrees of physical and/or intellectual disabilities (Rodwell & Aymé, 2014). Most rare diseases are genetic diseases, some type of cancers, autoimmune diseases, congenital malformations and also toxic or infectious diseases. There are between 6000 and 8000 officially identified rare diseases, but the prevalence of any given disease is low, less than 5 in 10,000 of the general population. Therefore, there is still little knowledge of causes and effective therapies, which poses variable challenges for medical and social services (Rajmil, Perestelo-Perez, & Herdman, 2010; Schieppati, Henter, Daina, & Aperia, 2008; Zurynski, Gonzalez, Deverell, Phu, Leonard, & Christodoulou, 2017).

In recent years, different studies have shown that a lack of diagnosis and knowledge about rare diseases presents challenges to the individuals living with them (Bogart & Irvin, 2017). Although, in many cases, it is possible to live a relatively regular life if a rare disease is diagnosed early and palliative treatment is available, sometimes the day to day realities of managing a rare disease and the challenges this presents remains unseen, leading to isolation, stigmas or discrimination (Somanadhan & Larkin, 2016). For children with rare diseases, besides different medical and social impacts, schooling is very often disrupted or impossible (EURORDIS, 2005; Zurynski, Frith, Leonard, & Elliott, 2008).

The schooling of children with chronic rare diseases can evolve in different ways. In general, depending on the child's unique circumstances or the policies and resources available in each community, these children may attend special schools, are homeschooled or are taught in the hospital setting (Closs, 2013; Hopkins, 2015). Current educational trends are designed to encourage inclusion of children with chronic illnesses in regular schooling among peers (UNESCO, 2009). These inclusion policies respond to the belief that normalizing the lives of children with chronic diseases is positive for children to avoid being ostracized. Compared to their peers, children with poor health form fewer social connections, impacting academic achievement, social

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functioning and self-esteem (Adams, Streisand, Zawacki, & Joseph, 2002). School is therefore a very relevant social environment, allowing them to feel part of a group while discovering their own passions and purpose. Additionally, the school is considered a social determinant of health with the greatest impact on children well-being (Coller & Kuo, 2015; Currie et al., 2012; Huang, Cheng, & Theise, 2013).

Educating students with rare diseases has to be governed by the principles of normalization and inclusion(Mukherjee, Lightfoot, & Sloper, 2000). Thus, any child with a rare disease has a right to access non-discriminatory, equal education that can also accommodate any necessary measures to make the different stages of education more accessible and inclusive.

In Spain, although there are special education schools for children with severe intellectual disabilities, in general, education legislation advocates for the inclusion of all children in mainstream schools (Coba, Grañeras, & Vázquez, 2010). According to the Law 2/2006 of Education, the objective of inclusion is to provide education that guarantees equal opportunities and non-discrimination with special accommodations for individual conditions relating to disability and chronic illness.

Inclusion of children with rare diseases in school poses diverse challenges for the educational system, teachers and other school staff. This research seeks to identify which aspects of the organization and practice of educational services hinder an inclusive educational and social experience for children with rare diseases.

2. Methods

A qualitative study was conducted using the social-critical paradigm as theoretical perspective. Research under this paradigm is sensitive to the needs of vulnerable groups of society and seeks to identify, analyze and contextualize them, focusing on practical recommendations to transform reality (Kincheloe & McLaren, 2005), so this study has the aim of outlining contextually practical developments that would be transferable to similar contexts.

2.1. Participants

As a part of a larger study (Roselló, Verger, Negre, & Paz-Lourido, 2018), this research was conducted in Mallorca, the largest island in the Spanish Balearic Islands. There is no exact record to identify the number of children living with rare diseases in the Balearic Islands; however, the Balearic Association of Families of Children with Rare Diseases (ABAIMAR) includes close to 100 families. Many of these children are enrolled in public schools and require regular medical care in hospitals and/or through primary health care centres.

The sample consisted of children and adolescents with rare diseases (n = 8), family members (n = 15) and school staff (n = 20). The selection of participants (43) for this study was based on the following criteria: the children (having a rare disease and attending primary and secondary education in public schools), family members (mother/father of a school-aged child with a rare disease) and school personnel (teachers educating children with rare diseases who are at different stages in their education in urban and rural schools, principals, support staff). The selection of participants was also based on family structure and socioeconomic backgrounds.

2.2. Recruitment

The recruitment strategy required key informants from ABAIMAR. This organization was firstly contacted and informed about the study. ABAIMAR contacted its members and several families volunteered freely to participate. Those families were contacted independently, provided with further explanation of the study and asked for sociodemographic information, including data related to the level and school attended by their children. The selected families (parents and/or their children) were then formally invited to participate in the study.

Information about schools with pupils with rare diseases was obtained both from ABAIMAR and through direct contact with schools. Principals, teachers and support staff were contacted and provided with an explanation of the study. Teachers and support staff from different education levels and schools were selected to participate. Inclusion criteria for participants was the following: a) children with rare diseases attending primary or secondary education in mainstream public schools. Children attending other forms of education, or not being able to hold an interview were excluded; b) mother or father of a school-aged child with a rare disease and c) staff members of schools with children with rare diseases enrolled.

The parents sample included members from different family size (number of siblings) and socioeconomic backgrounds (low, medium and high income). The staff school sample included members form rural and urban schools.

2.3. Instruments

The information was gathered through semi-structured in-depth interviews (n = 18) and focus groups (n = 4). Questions focused on the experiences of children, families and school personnel, focusing on the difficulties for a healthy, inclusive and equal participation of these children in school. The interview protocol also collected demographic data of the interviewees.

2.4. Procedure

Interviews took place at the students/families' homes or schools and focus groups took place in the University of the Balearic Islands. Sessions were recorded on two digital recorders and transcribed verbatim. Each data collection session was attended by two researchers, with one assuming the role of interviewer and another as observer, taking field notes describing both verbal and non-verbal communication, emotion and gestures. Data collection stopped when saturation on major themes was reached and no new information emerged (Patton, 2002). Both researchers present during the interview met shortly after leaving the family homes/interview room to document impressions and reflections so as to improve the accuracy and thoroughness of the descriptions.

2.5. Data analysis

Discourse analysis was utilized for data analysis (Antaki, 2008). After several readings, those elements that interfere with an inclusive and equitable education of pupils with rare diseases were selected, but particularly those aspects that referred to unjust situations, expectations, explanations for current practices and possible actions for change. For all interviewed groups, issues affecting children's experiences and posing difficulties for experiencing normalized schooling, were of particular interest.

A first analysis of the information was carried out separately by researchers for each interviewed group. Throughout the qualitative data analysis process, the four researchers met in person to discuss the emerging codes and categories, and to resolve discrepancies in interpretation. Given that the researchers had different backgrounds in health and education sciences, these meetings also provided a forum to explore and discuss biases that may be influencing interpretations of the data. Triangulation of information through different sources and methods was utilized as a means of methodological rigour (Mays & Pope, 1995).

Ethical issues in qualitative research were considered in all stages of this study (Richards & Schwartz, 2002). Informed consent was obtained from parents and school personnel prior to data collection and in the case of children, consent was provided by their parents. Ethical approval was received from the Committee on Bioethics of the University of the Balearic Islands. Taking into account that some of the

participants were children with rare diseases that are easily identifiable in the context, a description of the sample, including sensitive data, has been avoided in this article. As for the description of the results, names or data of diseases that may reveal the identity of the participants have been removed from the quotations. To ensure anonymity, each participant was assigned a code consisting of a letter: Child (C), Parent (P), School Personnel (S) as well as a number (from 1 to 15).

3. Results

3.1. Diagnosis

The lack of knowledge of the rare disease and the unknowns are among the main barriers to implementation of general protocols to meet a child's individual needs. There are also differences among the experiences of children with rare diseases in school; some children claim to have a poorly understood disease, but they have a definitive diagnosis. In other cases, there is no clear diagnosis, so the presence of symptoms and signs in the day to day or the occurrence of a disease crisis are the factors that distinguish these children from their peers. This reflects the added difficulty that people have without a defined diagnosis that reveals certain needs to address:

If you go in a wheelchair to school it becomes evident that you have needs. When your illness is not easily visible, you are told, "since I don't see your pain, I cannot appreciate how bad you feel and I find it hard to believe." (C4)

Not having a clear diagnosis is a problem for us. These children may be doing medical tests for several months and we do not have the support to make adaptations for these children without discriminating against the other children in the classroom. (S6)

Families and children refer to the perceived 'invisibility' of their situation, but also to the fact that sometimes schools do not take their situation seriously because these diseases, their symptoms and the effects are not always visible, officially diagnosed and, therefore, credible to others.

3.2. Official recognition

In the opinion of the families, the basis of the problem lies in the public administration of the educational, social and health sectors. There is a great lack of awareness about rare diseases, which makes it difficult to access resources, especially if a disease is not included in the list of known chronic diseases that require school support.

There is a lot of bureaucracy to comply with in order to have access to public services, to obtain a place in an educational centre close to the home or to subsidize medication costs. This leads families to feel excluded and discriminated against. They have to advocate for understanding, communication and coordination so that their children with rare diseases can enjoy equal opportunities along with the rest of the students:

"It is a problem when you don't get the public school close to your home just because the illness of your child is not in the list of diseases that give you preference among other families to get a place" (P7)

3.3. Accessibility

Accessibility refers to physical access to school properties and facilities but also to the adaptations and particular interventions that normalize a child's school experience. When children with rare diseases are starting school for the first time or their illness is becoming more disabling from one academic year to another, physical adaptations and environmental adjustments may be required to create a conducive environment. Further to the physical barriers to accessing school properties and facilities, other disease symptoms may affect the level to which a child can access and fully participate in school and they may not be visible to others.

It was difficult in the beginning with the wheelchair. There were many steps on the way to the classroom, but it was better when the school made some adaptations to the bathroom. (C5)

Feeling well (without a headache), being able to breathe without obstacles, getting to school, talking with friends, getting to class etc. That is a good day for me. (C3)

The attitudes of teachers represented an intangible barrier to accessing an equal education. In this way, the teacher's knowledge, understanding and awareness can determine the education of these children. Among the limitations for a child's participation are class sizes and problems following the teacher's explanations.

Sometimes there is a lot of noise in the class and I cańt hear the teacher. My classmates are not sensitive to how that affects me. (C6)

Everything is so easy. It's a problem of attitude, not of resources. (P4)

3.4. Absences

Absences from school are a topic of great concern for children with rare diseases and an added pressure on their chronic health condition. Appropriate resources and supportive staff seem crucial for diminishing the impact of absences not only in these students' outcomes but also in their health-related quality of life.

The last school I attended was the best of all. When we told them "I have this disease", the psychologist gave me support and all the teachers were informed. I got sick last December when the exams were taking place and I was hospitalized for a month. They told me, "you can complete the exams when you can," and so I wrote them in February. (C2)

In any case, communication via internet is highlighted as crucial, during hospitalization, for example, in order to keep up and seek help to complete homework and to ensure continuity in a child's education.

When I had to be hospitalized for a few days, my friends sent me the homework exercises via WhatsApp and explained what I needed to do. (C4)

3.5. Coordination

Parents argue that an improvement in coordination between institutions and professionals can lead to better adaptation to the educational needs of children and their health care, but also to improved communication to ensure a smooth progression year after year.

The student's teacher is very often the person who links with other professionals and families. This role is generally more definitive in the first years of education, becoming less so as the student progresses and more teachers intervene. In any case, the role of families seems key to cover a lack of coordination among health and education staff, particularly after hospitalizations.

With the health personnel, coordination is practically non-existent. Medical information is provided to us by the family. (S7)

There is very little information about the illness, that is a problem. (S4)

3.6. Curricular adaptations

Curricular adaptations are a key piece, because in some cases the symptoms or school absences threaten the appropriate follow-up of the study. It is striking, however, that the efforts of children with rare diseases to meet all the requirements of study and evaluation are not always met with positive feedback by teachers or peers.

Some of my classmates told me they felt it wasn't fair that I had access to

extra resources to pass the exams. I had to remind them that they can practice sports and do many other things that I can't. (C4)

The use of active and participatory methodologies or project work may be more complex for these students who cannot ensure consistent attendance, especially if they are not provided with guidelines for completing activities in an autonomous manner, at home or in the hospital.

If you miss a class, you don't have a book explaining what needs to be done. (C2)

Regarding specific subjects, physical education is one subject that the interviewees refer often to when expressing the need for adaptations.

For most of us with rare diseases, physical education is the most difficult subject. The teacher told me that my illness is not true; if nobody can see it, it doesn't exist. (C1)

Parents and teachers agree that if the curriculum is not adapted to sick children, they will always be at a disadvantage compared with other children.

3.7. Homework

For the teachers, homework compliance is usually required for all children. Parents recognize the importance of continuing education as much as possible with homework, because this normalizes children's schooling experience and also provides a distraction from their disease, although they expressed concerns about the impact on their children's health.

It is not always possible for children with rare diseases to follow the rhythm of their peers, highlighting an excess of homework to complete, regardless of attendance, which becomes very tiring. Particular concerns were expressed about completing homework in all different subjects and submitting it on time.

There is a lot of homework and many assignments. It would be great to reduce homework and have extra time for every subject. (C3)
Some children have teaching support at home and that is a big help for them (S3)

3.8. Autonomy

Autonomy varies greatly depending on the disease and evolving circumstances. In a time of crisis with pain, fatigue or medication, an individual can become very dependent. At other times, with the necessary support, autonomy naturally increases with support from school staff and families. Thus, the availability of supplementary personnel contributes greatly to maximizing the children's autonomy.

Not that they overprotect them … that they understand their situation and that they try to adapt to their needs. Nothing else. (P3)

New communication technologies in the form of mobiles or tablets, are seen as useful tools. However, and in spite of all the barriers and difficulties, in general, the participants indicate that the disease has forced them to be self-reliant and they try to depend as little as possible on other people. Participants highlight that having a rare illness causes a high level of self-knowledge. This is helpful to cope with their own situation and for disease management but that also helps them to be more sensitive to the problems of others.

3.9. Personnel resources

Teachers' discourses illustrate that in this context, it is always easier for schools to have dedicated educational support for children with learning disabilities than support staff for children who have a disease that affects them physically. For children, the teacher's support is crucial, as is the support from their peers, but additional personnel may make a difference in their school experience, and therefore is a consistent complaint of parents.

I have an assistant who helps me with everything, knows when I am tired, when I am not feeling well, calls my mother if necessary and also helps me when I cannot hear the teacher. (C1)
We parents always ask for more support for our children, because we do not want them to be hindered because of their illness. (P3)
We are teachers, we can give some support but we cannot do miracles. (S9)
I know I am part of the support team and I want to help, but there are issues that go beyond my duties and my training. (S3)

Support staff is key to meeting the health needs of children with rare diseases. The importance of training others to meet these needs, as well as to promote children's independence with respect to food, hygiene, etc., was emphasized. It was highlighted that very often the families play a key role in explaining, educating and making the staff aware of the characteristics and impact of the disease, but also in providing individual care.

I know the case in which the mother has go to school to give her child a snack or to provide treatment… and she has to leave her job for that. (S8)
It is scaring for some teachers to be involved in health assistance tasks for these children, even for simple things that anyone could do. (S6)

3.10. Peer support

The support of the peer group is fundamental for the participants, in particular, when there is a change of school or level. Peers provide key support for the follow-up of the classes when, due to illness, absence is inevitable, but they also provide emotional support and care.

My friends know it, they help me if I need anything or I feel bad, but I wouldn't tell the whole class because I don't want people to see me as special. (C7)

In any case, the trust and support usually focus on a small group of friends and not always on the whole class group. In addition, it is usually assessed as positive if there are other children with a chronic disease in the classroom, because they feel more integrated.

4. The majority of parents consider that children with rare diseases are more included in school when the disease appears early in childhood.

He's a very accepted and beloved child at school. They've grown up with him getting sick. (P10)
When the disease began to manifest itself with body twitches, things changed. Some laughed at her and she had such a bad time… that shatters me. (P6)

5. Discussion

The delay or lack of a clear diagnosis that occurs very often (Zurynski et al., 2017), are also among the difficulties to get the physical and curricular adaptations needed to have a normalized school experience in the studied context. Having a diagnosis facilitates the official recognition of the situation within the educational and health administration sectors. This influences access to schooling as well as the provision of specialised staff for care and educational support. Effective inclusion depends on the availability of personnel and resources, but also on the awareness and training about rare diseases among the teaching staff. Not having a diagnosis doesn't mean that the diseases

don't exist, so it is necessary to take into account the signs of it and also the non-visible symptoms that can affect a child's performance and participation.

Communication is very useful during hospitalization, but also helps to create the environment, learning and attitudes required to facilitate a smooth and welcoming transition after crisis. Having access to internet and communication technology is crucial for the children to keep updated with the education requirements during absences. It is important that health professionals empower children and families to understand and manage the disease, as well as train and coordinate with teaching and other support staff. Defining a link person and developing a protocol of communication is crucial for both the education and health sectors, but it also reduces the stress on families.

Information provided by the health professionals is key to facilitate the day to day schooling, the elaboration of realistic education goals and the curricular adaptations (Jackson, 2000). In this study, this includes also redefining the amount and type of homework, as well as home teaching support to avoid negative influences on health-related quality of life. It is relevant to encourage the autonomy of the student in the school and also to establish the framework of trust so that asking for help is facilitated throughout an environment of mutual understanding.

Participation of children with rare diseases in school revealed concerns in all sectors interviewed, and the results are consistent with previous studies (Nabors, Little, Akin-Little, & Iobst, 2008; Castro & García-Ruiz, 2016). For teachers, the main fear is not having the information and training necessary to offer an adequate response. Furthermore, teachers referred to the fear of liability and the possibility of performing some inappropriate intervention resulting in an unintended outcome for the student. These fears intensify depending on the severity of the disease and could be alleviated by the presence of specially-trained support staff. For the family, the main fear is about ignorance about the disease, especially on the part of the educational community. In general, there is some uncertainty regarding the treatment that students will receive in the educational centre. For children the main fear is peer discrimination or not being understood by the teachers, what may interfere their performance, disease management and wellbeing (Beachamp & Deatrick, 2015).

The need for knowledge about rare diseases in general and the situation of each student in particular was stressed in order to adapt the educational intervention as much as possible. This information is also crucial to sensitize the educational community, especially peers, in order to avoid possible situations of discrimination, ridicule, incomprehension and rejection, which may occur in the school environment. It is necessary to respect the confidentiality of the student's situation. In some cases, the fear of rejection can deter students and families from adequately informing schools, which illustrates the importance of deepening the work on inclusion and acceptance.

Results of this study highlight the difficulties, but also the opportunities that the schooling of children with rare diseases poses. Having a child with a rare disease in the classroom provides an opportunity to create diversity, acceptance and inclusion, with impact in quality of life. Therefore, measures taken shouldn't be seen as a great effort for a single child but as an intervention in the whole school system that can be seen as beneficial for all.

Results are consistent with others describing the repercussions that diverse rare diseases have on the child and on his/her schooling process in different contexts. (Bendixen, Senesac, Lott, & Vandenborne, 2012; Fernández & Grau, 2014; Hill, Baird, & Walters, 2014; Lewis-Jones, 2006; Shaw & McCabe, 2008; Paz-Lourido, Negre, de la Iglesia, & Verger, 2020). This shows that, despite the existence of many diseases under the umbrella of the term "rare diseases", many aspects are common and can serve as a basis for the establishment of policies focused on an inclusive and healthy schooling for these children.

The availability of adequate resources, the training of teachers and the establishment of a communication protocol with health professionals is crucial. Different studies (Domaradzki & Walkowiak, 2019; Jonas et al., 2017; Kopec & Podolec, 2012), highlight the importance of starting training on rare diseases already in the university (Paz-Lourido, Negre, Verger, & De Benito, 2018), so that professionals from different disciplines have a real and non-stereotyped vision of this type of affectation and its implications. But, in addition, it is necessary to reinforce training in skills such as communication and coordination, also requiring the implementation of interprofessional education programs. Furthermore, it is necessary to improve the current knowledge and awareness of the educational administration, teachers and students about the implications of rare diseases. The participation of families in the process is needed, not only to promote an inclusive and safe education for their children, but also to contribute to institutionalize long-term practices.

6. Conclusion

A given rare disease affects a minority of school-aged children, but the provision of appropriate education and care is a complex process influenced by the health condition of the individual child, the level of empowerment of families, the availability of resources and the commitment of the school and health care providers. The delay or lack of a clear diagnosis is among the challenges to obtaining the adaptations required. This highlights the need for a strategic plan to address the children's, families' and teaching staff's needs as well as regulate and institutionalize practices in the school.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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