



BMJ Open How congenital Zika virus impacted my child's functioning and disability: a Brazilian qualitative study guided by the ICF

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ABSTRACT

Introduction The Zika virus outbreak in Brazil has had devastating social, medical and financial consequences for families. Both researchers and clinicians are measuring longer-term outcomes to understand the impact of the Zika on child development, functioning and disability. Outcomes and tools used to measure them are very varied and we are unclear how meaningful they are to families and children. This study aimed to identify the parents' perspectives on relevant areas of functioning and disability that should be included as outcome measures for children with congenital Zika syndrome (CZS), as guided by the International Classification of Functioning, Disability and Health (ICF).

Methods This qualitative study included parents or caregivers of children aged 0–5 years with confirmed CZS from two states in northeastern Brazil. Interviews were conducted using focus groups. Content mapping followed the WHO's ICF linking rules. Three raters analysed the content using NVivo V.11.

Results Thirty-two caregivers participated in six focus groups, 88% were mothers with an average age of 30 years. Most children were male (59%) and all were level V (severe) to on the Gross Motor Function Classification System (GMFCS). Overall, 825 themes were mapped to 36 ICF categories. Although parents mentioned areas across all ICF domains, they reported that areas of mobility, eating and recreation were most relevant for them. In addition, environmental factors were highly identified as barriers, specifically services, policies and access to assistive devices. The most predominant facilitators within the environment were; immediate family support, kind relationships with therapists and support from the extended family.

Conclusions Although parents emphasised issues related to mobility, their greatest concerns involved environmental factors, such as access and quality of health and social services, systems and policies. These results reinforce the importance of including parents' perspectives when selecting or developing outcome measures for CZS.

INTRODUCTION

The Zika virus (ZIKV) was identified in Brazil at the beginning of 2015. During this time,

Strengths and limitations of this study

- This is the first International Classification of Functioning, Disability and Health-based qualitative study describing caregivers' perceptions on relevant areas of function in children with congenital Zika syndrome in Brazil.
- Few studies have previously undertaken research to understand parent's views on the issue of what outcome measures should be considered in neurodevelopmental disorders.
- We had limited representation of men within our sample as the main caregiver was predominantly women.
- Our study was limited in terms of numbers of participants and region in Brazil, limiting the generalisability of our study.

rates of microcephaly and other congenital brain abnormalities increased, suggesting a causal relationship between the two.¹ Since then, clinical reports have documented the teratogenic effect of ZIKV in pregnant women, particularly when infected in the first trimester.^{2–4} The most prominent anomalies for children with congenital ZIKV is microcephaly, but other manifestations such as, spasticity, seizures, eating difficulties, irritability, ocular abnormalities, hearing loss, calcifications, cortical disorders and ventriculomegaly have been described.^{5–7} There is still no clear definition of exactly what is included in congenital Zika syndrome (CZS). As a result, surveillance studies are underway to identify the wider spectrum of congenital malformations, which may be associated with ZIKV infection.^{8,9}

A precise estimate of ZIKV infection incidence is difficult to determine due to variations in case ascertainment between countries and only a small number of children identified

with manifestations of the more severe congenital ZIKV syndrome.¹⁰ There are currently 3406 confirmed cases of children with microcephaly and/or other neurological signs due to CZS in Brazil, with a further 2596 cases under investigation.¹¹

Given the severity of the syndrome, the scientific community has mobilised efforts to understand the mechanisms of this health condition and to measure long-term health and neurodevelopmental outcomes of children with this condition. Presently, a large variety of heterogeneous tools and outcomes are being used, often which causes confusion and lack of ability to conduct meta-analyses and syntheses of data. Furthermore, most tools chosen are those chosen by epidemiologists and researchers who may have little understanding of the what is most relevant to parents and families with children with this condition. Primarily, tools to measure child development are used; not always that relevant when functioning for these children may be very limited. As such, creating a standardised core outcome set (COS) for CZS will reduce the heterogeneity of the studies and further enable clearer synthesis and data sharing between studies.¹²

The Core Outcomes Measures in Effectiveness Trials is an initiative aimed at identifying and creating a core set of outcomes for any clinical health situation. This is often conducted through a process of systematic reviews of outcomes measured, consensus work as well as the involvement of families who support the development of these outcomes in order to ensure that researchers consider outcomes that are most relevant and appropriate to the patient's needs.^{13 14} As part of COS development, a framework is usually used to enable outcomes to be classified and considered for finalisation in a COS. In the case of neurodisability and neurodevelopmental disorders, a helpful framework can be the International Classification of Functioning, Disability and Health (ICF) which provides a standard language and framework for health states.¹⁴ The ICF includes both functions and structure of the body and activities and participation of the child and can be used as a guiding framework providing a common language for describing the dynamic interaction between the person functional abilities and the role of the environment.¹⁵

Currently, there is no COS for children with CZS. To fill this gap, we aim to develop a COS for children with Zika and other congenital infections. This project is coordinated by the University of Liverpool in partnership with the University of Victoria (Canada) and Federal University of Rio Grande do Norte-UFRN-FACISA (Brazil). This paper describes a qualitative study that is part of the first phase of the COS for CZS project.¹⁶ The specific objective of this qualitative study is to identify the parents' perspectives on relevant areas of functioning and disability which should be included as outcome measures for children with CZS, guided by the ICF.

METHODS

This study used a qualitative methodology with an exploratory approach through focus groups. We chose to use

a qualitative approach as it enables investigation and an in-depth understanding of the perspectives and experiences of parents/caregivers of children with CZS. Focus groups, in particular, provide the potential to explore and clarify points of view and reveal dimensions of understanding which would be less easily accessible in other data collection formats.^{17 18}

Parents/guardians signed a Consent Form after being provided with an information sheet which was read out to them. Parents also signed consent for voice recording and use of images.

Participants with important common characteristics were purposively selected by members of the research team, through active search by phone call or direct personal approach. The inclusion criteria included: (1) being parents/caregivers of children with confirmed diagnosis of CZS by PCR or presumed diagnosis based on obstetric ultrasound, transfontanelar ultrasound, CT and MRI, (2) child with congenital CZS aged 0–5 years and (3) living in the area covered by the study (states of Rio Grande do Norte and Paraíba) and attending the respective rehabilitation services.

The rehabilitation centres are public services linked to research institutions and higher education in the region. This study did not include parents whose children had congenital syndromes due to other aetiologies.

All parents responded to a sociodemographic questionnaire, applied by the researchers prior to the focus groups with information about; their relationship with the child, marital status, age, income, government benefit, education, housing and self-reported health, in addition to information from children about gender, age, mobility, rehabilitation, frequency day care centres or schools, and difficulties with vision, hearing, sleep and epilepsy. This questionnaire was to ensure good understanding prior to rolling it out to all respondents. Two research assistants were involved in the data collection. In each centre, the physiotherapist who accompanied the children classified their motor abilities using the GMFCS. This is an age-specific scheme designed for children with cerebral palsy (CP) based on five levels of gross motor function, ranging from level I (most able) to level V (least able)¹⁹ and provided some clear information on the severity of the children whose parents took part in the study. The study flow chart can be viewed in [figure 1](#). We used the Consolidated criteria for Reporting Qualitative research guidelines to guide us with our study methodology and write up.

The focus groups were carried out between September 2018 and January 2019, by research assistants (TCC and EL), trained both in qualitative studies and in conducting focus groups. We continued to do focus groups until saturation was reached—where testimonies became repetitive, predictable and were not providing any additional information. Saturation was achieved by the sixth group. We did not exceed six parents/caregivers per group in order to enable effective participation of the participants and appropriate discussion of themes. Of the 36 parents identified and invited to the study, 32 agreed to participate.

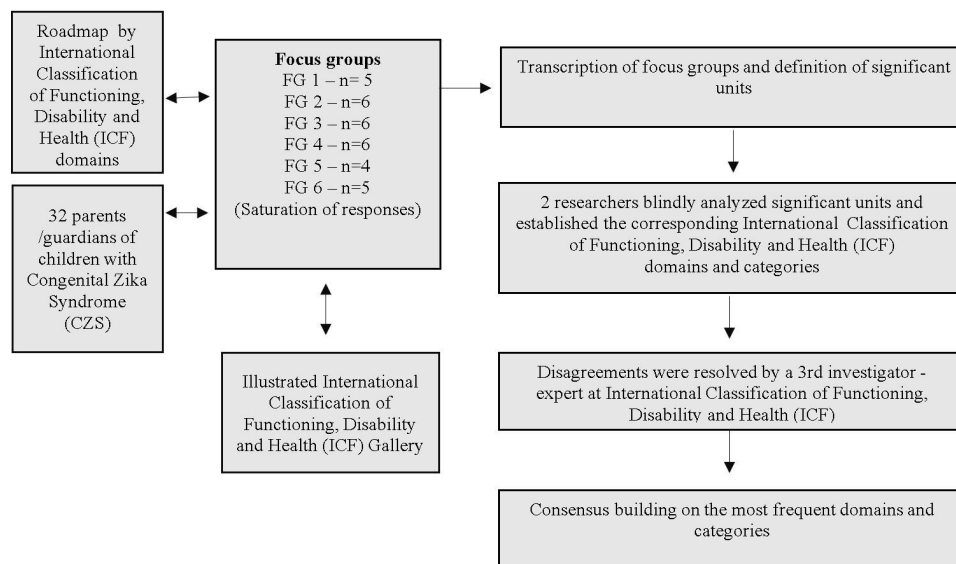


Figure 1 Study flow chart. ICF, international classification of functioning, disability and health.

A questionnaire adapted from a previous ICF-based qualitative study was used to conduct the focus group, covering the different ICF domains (see online supplemental material 1).²⁰ Visual tags were produced with images from the ICF illustrated gallery (see online supplemental material 2)²¹ to assist in understanding the concepts, as studies indicate that visualisation has the potential to support data production during the qualitative interview process.²² The duration of the focus groups ranged from 60 to 90 min. The participants were given a therapeutic toy developed by research team at the end of the groups, called ‘fun fishing’, in order to thank the parents for participating in the study. They were encouraged by the professional team to use it as a therapeutic toy for stimulation of their children at home and to promote fun. All groups were recorded and later transcribed in full. Names of participants and any identifying characteristics were excluded from the transcripts. The transcribed content was analysed by three researchers experienced in qualitative research (TCC and EL). They split the content into significant units with using NVivo software, V.1.0 (QSR International, 2019), and associated them with each ICF domain and category using the WHO’s linking rules²³ as follows: TCC and EL, trained in ICF, performed a blind reading of the content and established the ICF domain and category for each significant unit of the interview to which it was judged to be relevant versus, a specialist in ICF and with extensive experience in childhood disability, analysed the disagreements of the two researchers, establishing consensus in relation to the domain/category of the ICF regarding the significant units.

Next, the content was analysed by the researchers who interpreted the data through an inductive and deductive analysis process based on a permanent dialogue throughout the process to ensure consistency and reliability of the interpretations. Any verbatim which did not exceed ‘five mentions’ was discarded as it was felt not to

be representative enough of the data. The frequency of each ICF category in the statements of parents/caregivers was used as a parameter to determine the order of importance of ICF domains/categories. After this process, the content was translated from Brazilian Portuguese into English by a bilingual member of the research team and the content checked by two others, to ensure that there was no loss of meaning.

Aspects of credibility, transferability, reliability and confirmability were considered during all stages in order to guarantee the quality of the qualitative research.²⁴ Credibility was ensured by thoroughly conducting six focus groups until saturation was reached, with subsequent blind analysis, review and triangulation, and then consensus being reached after meetings and debates regarding the interpretation of results. The researchers have robust training in the area of childhood disabilities and in the use of the ICF for neurodisabilities. Transferability occurred through observation of the rigour to which the research group stopped to describe how the data was obtained through the focus groups, the selection and description of the sample, which in this case involved the participants. Reliability was guaranteed by detailing the data collection processes, presenting the multiple steps followed by the researchers, and showing how the pair analysis and data interpretation took place. A measure of reliability through using the kappa statistic was also used to verify the agreement between the judges, with results indicating almost perfect agreement (0.916) considering 95% CIs. Finally, verification was achieved through a peer discussion of the data at each stage of the analysis by the research team.

Patient and public involvement

Families were not involved in the design, recruitment or conduct of the study. However, the results will be presented to families, professionals and managers at each

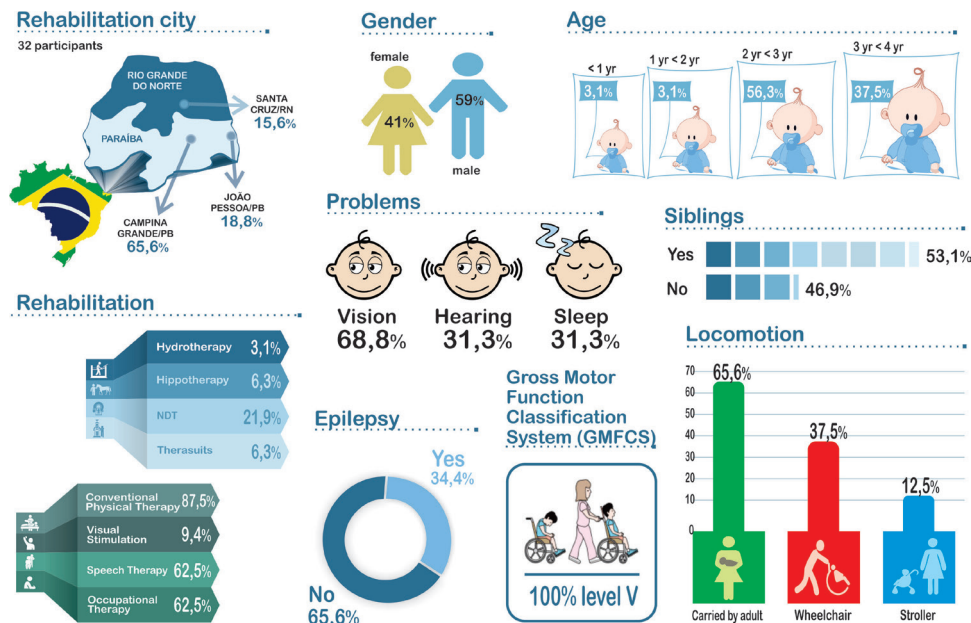


Figure 2 Sociodemographic data of children.

participating centre, with a view to discussing strategies to meet the needs of children with CZS and their families.

RESULTS

Six focus groups were conducted with 32 caregivers of children with severe neurodevelopmental disorders associated with CZS. Information related to children can be found in figure 2 and the characteristics of families are in figure 3. The average age of the children was 32.5 (SD=6.2) months, with a predominance of males, all with severe motor impairment on, the GMFCS. Although

none of the children walked, only 37.5% of them had a wheelchair.

Thirty-six categories of the ICF were identified, as demonstrated in figure 4 (personal factors were expressed only minimally). This figure represents the parents' perspectives on relevant areas of functioning and disability of their children.

The parents mentioned relevant areas that covered all ICF domains, but a greater diversity of categories was observed in the domains of activities and participation and body functions. However, the environmental factors

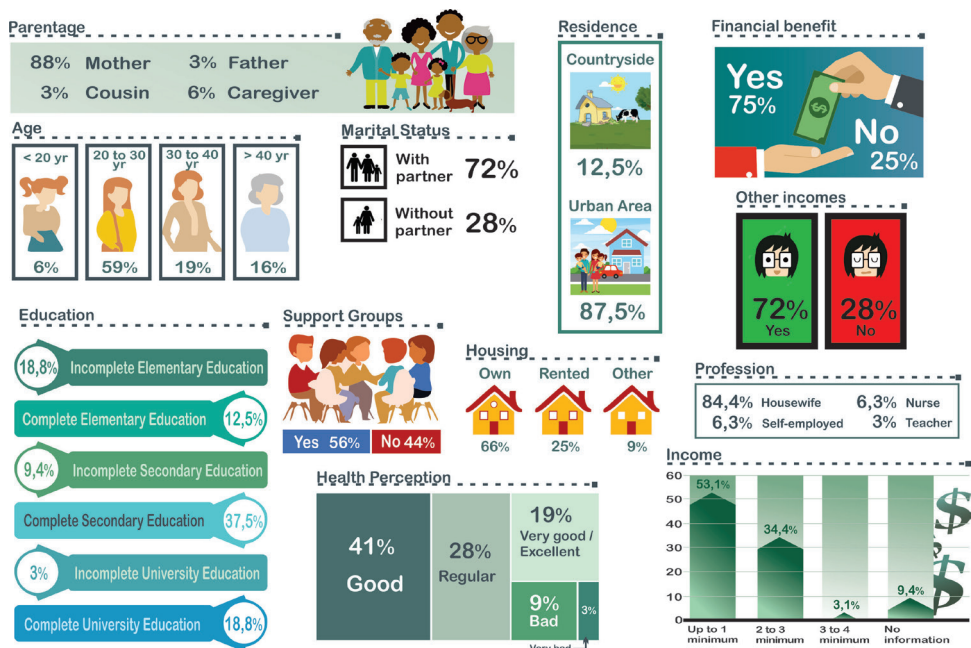


Figure 3 Sociodemographic data for parent/caregivers.

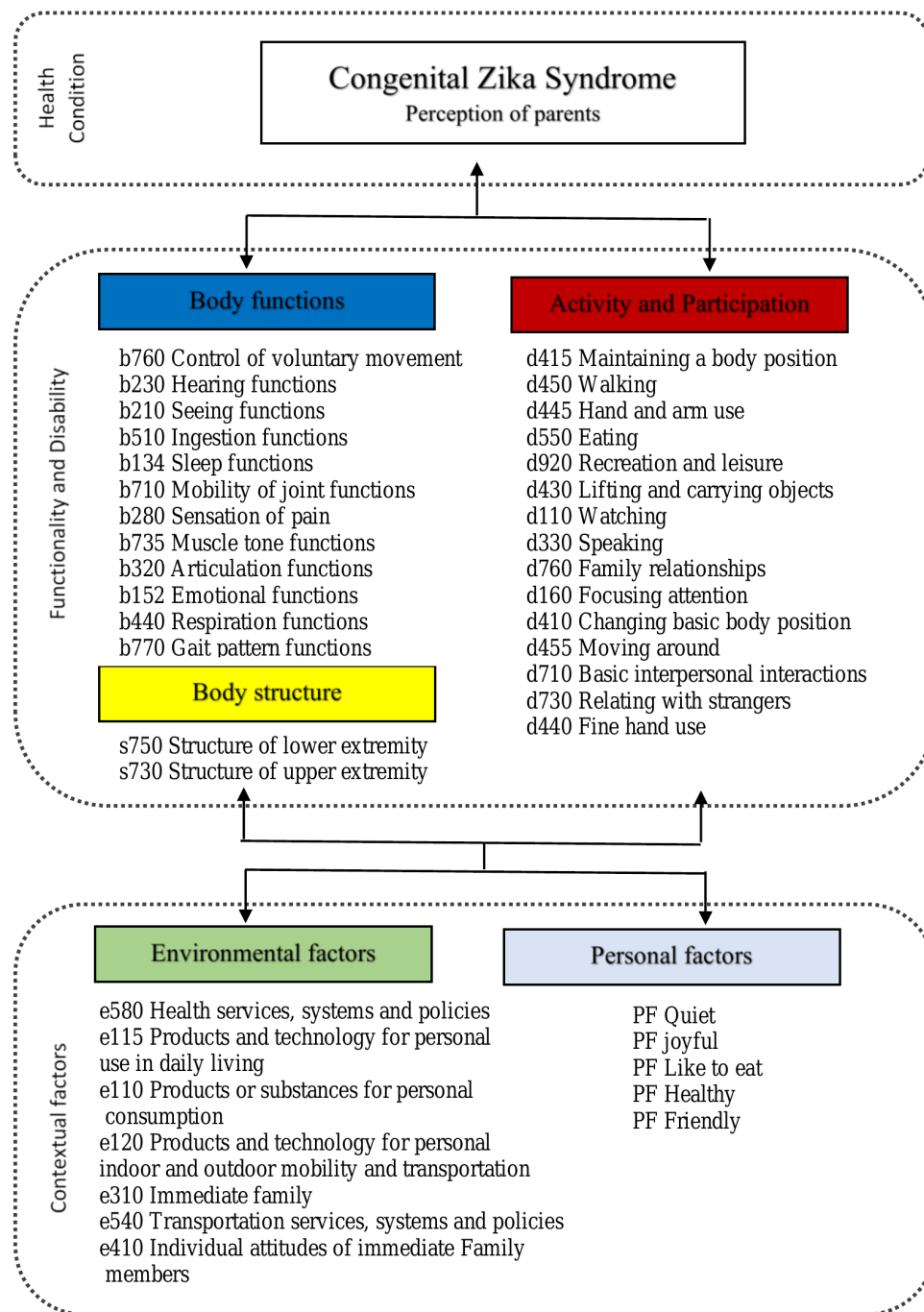


Figure 4 ICF categories representing the parents' perspective. ICF, international classification of functioning, disability and health.

domain led the ranking of 12 categories, as can be seen in [table 1](#).

[Table 2](#) shows the distribution of categories related to the environmental factors domain in detail.

Among the categories, health services, systems and policies (e580) was the barrier most expressed by parents, receiving 59 mentions. This category includes the prevention and treatment of health problems, the provision of rehabilitation services and the promotion of a healthy lifestyle. The following verbatim demonstrates a mother's desire to have access to rehabilitation services in her own city.

Also that in Alagoas state has been the same possibilities that here in Campina, to don't need to move from one place to other, it's so complicated spend 3 months here, searching treatment that there it should have. I don't know they can't leave this treatment there, to every states have, for us don't need to move a lot to do a treatment. For them could at least sit, maintain their trunk, catch and walk. Mother 20.

Other barriers reported in this area included; lack of information or professionals specialised in the management of CZS and the difficulty in transport to travel to

Table 1 Table demonstrating the ranking of the 12 most frequent categories of the ICF mentioned by parents

Category	QTY	Domain
1° e580 Health services, systems and policies	59	Environmental factors
2° b760 Control of voluntary movement functions	37	Body functions
3° e115 Products and technology for personal use in daily living	33	Environmental factors
4° d415 Maintaining a body position	33	Activities and participation
5° e110 Products or substances for personal consumption	31	Environmental factors
6° b230 Hearing functions	31	Body functions
7° b134 Sleep functions	31	Body functions
8° d450 Walking	28	Activities and participation
9° e120 Products and technology for personal indoor and outdoor mobility and transportation	25	Environmental factors
10° b210 Seeing functions	24	Body functions
11° d445 Hand and arm use	23	Activities and participation
12° s750 Structure of lower extremity	22	Body structures

ICF, international classification of functioning, disability and health.

rehabilitation services in other larger cities. Examples of this are evidenced in the statements below.

I guess that it would help a lot if the access is facilitated, in our city, if I had physiotherapy in my city, sure I would go more often. Mother 03.

I would like that science produces medicines for this disease, because it is a new disease. Another thing, a great difficulty for me, is the absence of answers... you go to see a doctor with your child, and the doctor is stalling, he never tells you the reality... Mother 24.

If our city would have treatment... moving is tiring. And if when we come, we were taken care of... We suffer from these experiences, some days I have spent many hours travelling... Mother 04.

Some parents pointed to assistive products and technologies as facilitators. They described how adapted or specially designed equipment improved the functioning of their children and contributed to greater participation;

For E*, to facilitate activities, first I put her glasses on... once I take her glasses off, her vision becomes worse... if I put the glasses on, she becomes much more animated. Mother 06.

The support of the nuclear family was expressed by participants of all focus groups as a major facilitator to their environment, as described below.

What helps? I have a lot of support from my husband and my sister. I live close to my sister... my parents don't live in the same city as me, but they always are present... Always... from the beginning they have been present. My family helps me a lot, and this helps me, when I want to go out and can't take her with me... I leave her with my sister. The family support, it's the main factor that helps me, because alone, it's hard. Mother 14.

Table 3 presents the categories referring to the activities and participation domain.

Table 2 Table of areas of the ICF considered important for parents within the area of environmental factors

Environmental factors		
e580 Health services, systems and policies	59	33.0%
e115 Products and technology for personal use in daily living	33	18.4%
e110 Products or substances for personal consumption	31	17.3%
e120 Products and technology for personal indoor and outdoor mobility and transportation	25	14.0%
e310 Immediate family	16	8.9%
e540 Transportation services, systems and policies	9	5.0%
e410 Individual attitudes of immediate family members	6	3.4%
Total	179	100.0%

ICF, international classification of functioning, disability and health.

Table 3 Table demonstrating areas of the ICF within activity and participation found as important to parents

Activities and participation		
d415 Maintaining a body position	33	14.5%
d450 Walking	28	12.3%
d445 Hand and arm use	23	10.1%
d550 Eating	21	9.3%
d920 Recreation and leisure	19	8.4%
d430 Lifting and carrying objects	15	6.6%
d110 Watching	15	6.6%
d330 Speaking	12	5.3%
d760 Family relationships	11	4.8%
d160 Focusing attention	11	4.8%
d410 Changing basic body position	9	4.0%
d455 Moving around	9	4.0%
d710 Basic interpersonal interactions	8	3.5%
d730 Relating with strangers	7	3.1%
d440 Fine hand use	6	2.6%
Total	227	100.0%

ICF, international classification of functioning, disability and health.

As shown in [table 3](#), the most often expressed categories were those related to movement of children, such as Maintaining a body position-d415, Walking-d450, and Hand and arm use-d445. Such aspects were pointed out by the parents as being responsible for limiting activity and restricting participation in daily activities, as evidenced in the statements below.

M* has difficulty maintaining body position, when I put him in standing position supported by the wall, he can stay a long time. Sitting... he also doesn't sit alone, but if you put him in sitting... he stays there... He doesn't go from lying down position to sitting, but from sitting to lying, he can. Mother 15.

Eating... she holds it but doesn't know how put it in her mouth. Mother 01.

His major difficulties are to grasp things. He doesn't grasp and we need to put in his hands and then he holds it. If he needs to pick up something, he can not do it, but he holds and object if I open his hand for him Mother 08.

I guess it's so difficult for these children; they don't walk and don't sit yet. If, when I arrive in a place and it has a wheelchair I try and sit him in it, he still can not sit in it. Mother 17.

Finally, the areas of Body Function and Structure identified most by parents is shown in [table 4](#).

Control of voluntary movement-b760 was the most common category mentioned in the domain of functioning. Many parents expressed concerns about their child's voluntary movements (both simple and more

Table 4 Table demonstrating the categories of D body functions and structures (within the ICF) identified as important by parents

Body functions		
b760 Control of voluntary movement functions	37	16.70%
b230 Hearing functions	31	14.00%
b210 Seeing functions	24	10.80%
b510 Ingestion functions	19	8.60%
b134 Sleep functions	31	14.00%
b710 Mobility of joint functions	18	8.10%
b280 Sensation of pain	16	7.20%
b735 Muscle tone functions	15	6.80%
b320 Articulation functions	10	4.50%
b152 Emotional functions	8	3.60%
b440 Respiration functions	7	3.20%
b770 Gait pattern functions	6	2.70%
Total	222	100%

Body structures

s750 Structure of lower extremity	22	78.60%
s730 Structure of upper extremity	6	21.40%
Total	28	100%

ICF, international classification of functioning, disability and health.

complex) as well as their child's difficulties with coordination as well as use of their upper and lower limbs.

Control of movements... L* has a lot of difficulties, she can't lift her arm or her hand. With regards to her ability to move, she also has difficulties, she can't lift her arm and hand. She doesn't have a lot problems with her legs, but she can't move her body. Mother 24.

Parents also pointed out problems related to; Hearing functions-b230, Seeing functions-b210 and Sleep functions-b134.

Her hearing is only good on one side, on the other side, it doesn't work. We are doing a raffle to earn money to buy a device, because when she was examined it showed that she can hear with her left ear, but on the right, she doesn't hear anything. Mother 22.

About his vision, he doesn't see everything, his vision is low, he has difficulties. Father 01.

He has sleep difficulties, but when he falls on sleep, he sleeps the whole night. Mother 28.

With regard to 'body structure', the category relating to Structure of lower extremities-s750 most commonly emerged within our parent focus groups. Many parents described issues with foot positioning and how this prevented walking and standing.

The knees, it is something that I guess she won't do. And her feet, to walk, that will be a great difficulty, because she has a dislocation. We don't know if she will walk or if she will need a wheelchair for the rest of her life. Mother 27.

About S*'s little foot... when I put him in standing position, his foot turns to the side. Mother 10.

DISCUSSION

This pioneering research is the first to describe the perceptions of parents and caregivers regarding their understanding of the issues for their children with congenital CZS as placed within the ICF framework. Parents/caregivers highlighted the importance of environmental factors and motor function for their children with CZS. These factors must, therefore, be taken into account when constructing a recommended core set of outcomes to be measured in CZS. The use of the ICF as our guide for this study has enabled us to provide a holistic framework for considering perspectives that extend beyond the issues with body functions and structures for children with CZS.

Despite the number of new cases of CZS stabilising, the complex clinical presentation of CZS and its effect on children's health means that both standardised and individualised care is needed.²⁵ Researchers need to consider a holistic approach to their measurement of outcomes when following these children. The diversity of needs of these children (and families) with CZS and neurodevelopmental disabilities is wide.²⁶

Several ICF categories were identified by parents as very relevant and which must be considered and advocated for within the global context for the creation of a COS for CZS. This is particularly the case for researchers who will be measuring the effect of rehabilitation and support interventions for families.²⁷ In particular, the importance that parents place on environmental factors for the well-being of their children demonstrates the real need to include this environmental context as an aspect to be assessed in the follow-up of children with CZS.^{28 29}

Our study has demonstrated that the lack of trained professionals to support families is a major issue for parents that needs to be addressed.³⁰ Furthermore, parents expressed a great need for information about the condition of their children.³¹ The Centers for Disease Control and Prevention has produced a pocket guide summarising paediatric guidelines on initial assessment and outpatient treatment for CZS.³² Resources such as this could be more often provided for parents, particularly if given in a caring and sensitive manner with space for parents to reflect and ask questions. It is clear that a carefully planned public health approach which targets the needs of parents and families and provides adequate care and support for children and families, is still lacking.^{33 34} Addressing the environmental issues which hinder many parents and families' every day functioning is the most crucial aspect of this, and the one that will make the most difference for families and children quality of life.

Many parents/caregivers in our study expressed a desire to receive treatment and support in a single place or city. Moving from place to place for services and different types of rehabilitation all the time, is a real barrier for families. Parents in our study signalled a definite need for reorganising health services in a way which would provide more of a 'one stop' approach for supporting them. This has been highlighted in other studies.³⁵ Furthermore, lack of access to services (mainly due to distance, cost and lack of availability) was a massive issue for families of children with CZS.³⁶ From our study, it is clear that services for support and rehabilitation in a single location would minimise problems of low attendance and/or avoidance of services. Lack of attendance interferes hugely with enabling good outcomes when using focused, context-based and evidence-based rehabilitation.³⁷

Parents who took part in our study voiced particular concerns around aspects of their children's movement. This permeated the domains of activities and participation, functions and body structure and was, of course, expressed as a limiting factor in their participation in daily and leisure activities. It was clear that parents were disappointed and desperate for a change in mobility of their children and had had little counselling about adaptations to support children in their daily lives through other means. The focus still seems to be on the perspective of 'fixing' the disability through therapies.³⁸

Alongside this, parents voiced their desires relating to gait acquisition (walking) in the context of their comparison of their children with typical children. This is well documented in previous research with children with CP.³⁹ We know that many parents who have children who will never walk often still resist early introduction of mobility aids (such as adapted toy cars or wheelchairs). This is despite the fact that studies involving children with CP with severe motor impairment demonstrate very positive results when using these adaptations in terms of autonomy, self-esteem, social skills and participation.⁴⁰ Recent studies have shown that promoting participation in children with physical disabilities can, in itself, result in improved body function and structure.⁴¹

Our findings also showed that parents concentrate on the child's impairments and that parents have high expectations for healing or a cure. Unfortunately, in Brazil, there is little acceptance of disabled children for what they are within their context. This negative view of disability is common for parents with children with similar conditions.⁴² Parents in Brazil tend to focus on their children's ability to perform daily activities as well as the environmental barriers at home, school and in the community. This demonstrates a need for action, including education, at a local and national level to change attitudes towards disability. One example which could be advocated is the use of accessible and open access educational tools such as MY ABILITIES FIRST.⁴³

Our research has demonstrated what areas of the ICF parents of children with congenital infections such as CZS consider important. This information is vital to have

when attempting to establish a COS for CZS. We also know that it is essential to also consider the child's own perspective as to what he/she considers to be relevant in outcome measures, however, children with CZS have limited communication and in our case, were not yet old enough to express their opinions.

We acknowledge that parents' perceptions of the needs of their children with CZS will change throughout their lives with further studies being necessary to understand this over time. Professionals will need to remain vigilant as scientific knowledge about the impact of CZS will evolve in the coming years.⁴⁴ However, due to the similarity with CP, many professionals working with these children in the early years are focusing on ways to provide devices to aid with functioning, stimulate child development, prevent worsening of health conditions and to support caregivers. Over time the focus will shift to supporting inclusion, independent living and to continuing to maintain health and function.³⁶

There were a number of limitations in our study which must be taken into account. The sample was extracted from three Brazilian cities, from public or not-for profit rehabilitation centres. In this way, our findings may not represent the perspectives of all parents of children with CZS and should not be generalised. Our study generated the views of mothers predominantly with very few fathers taking part. Fathers may have a very different perspective and may have provided very different results to our study. Finally, within this study, we were unable to take the views of the children themselves into account. This would be important and relevant to consider in the future.

CONCLUSION

This is a unique study which aims to understand the views and perception of parents with regard to the needs of their children with CZS guided by the ICF. Although the parents did concentrate on issues related to movement abilities of their children, overall their emphasis was centred around environmental factors. These factors included services, systems and policies for prevention and treatment of their children as well as factors which would enable a healthy lifestyle to promote the physical and psychological well-being and social status of their children.

Our results reinforce the importance of including the parents' perspective in the development of a COS. Parents are the ones who live and experience the main limitations and potential of their children and in our study, they highlight the urgent need for environmental changes to improve the lives of children with CZS and their families in Brazil. In the future, when children with CZS are able to express their own opinions, we should also hear their views as to what they consider relevant for outcome measures.

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Contributors VS, MG and EL designed the study. TCC recruited the participants and conducted the interviews. VS, MG, EL and TCC reviewed and refined the data. TCC wrote the article. VS, MG, EL, MG, JST and AGM revised the article. TCC received qualitative research training through participation in a qualitative health research methods course at the Federal University of Rio Grande do Norte/Brazil.

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Competing interests None declared.

Patient and public involvement statement Families were not involved in the design, recruitment or conduct of the study. However, the results will be presented to families, professionals and managers at each participating centre, with a view to discussing strategies to meet the needs of children with CZS and their families.

Patient consent for publication Not required.

Ethics approval This research was approved by the Ethics and Research Committee of the Faculty of Health Sciences of Trairi/Federal University of Rio Grande do Norte (2.357.552), it was also reapproved at Liverpool University Ethics Committee (#2083) and developed in three Brazilian rehabilitation centres for CZS in the states of Rio Grande do Norte (Physical Therapy School Clinic at UFRN-FACISA, in Santa Cruz) and Paraíba (Centre for the Care of Children with Microcephaly at the Professor Joaquim Amorim Neto Research Institute - IPESQ, in Campina Grande, and Physical Therapy School Clinic at UNIPE, in Joao Pessoa).

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