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'There was nothing, just absolute darkness': Understanding the needs of those caring for children and young people with complex neurodisability in a diverse UK context: A qualitative exploration in the ENCOMPASS study

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Abstract

Background: Children and young people (CYP) with complex neurodisability experience multiple physical, communication, educational and social challenges, which require complex packages of multidisciplinary care. Part of the holistic care required includes supporting the families and parents/caregivers. The aim of the wider study was to introduce a new programme ('Ubuntu') to parents/caregivers and healthcare professionals (HCPs) in order to test the feasibility and acceptability of the concept and content, with the goal of potential adaptation for the UK in mind. Data collection and analysis uncovered rich data on caregiving journeys, navigation of health services, and perceived service gaps. This paper focuses solely on these topics. Further papers will report on the feasibility and adaptation data.

Methods: Two rounds of semi-structured interviews were conducted with 12 caregivers of CYP with complex neurodisability and six HCPs from a variety of disciplines, recruited from a community child health service in London Borough of Newham, UK in 2020. The interviews included open-ended questions to explore caregiving journeys, experiences of navigating health services and perceived service gaps. Transcripts were analysed using a data-driven inductive thematic analysis.

Results: Three themes were identified that related to the aim of understanding caregivers' experiences and unmet needs relating to current service provision. These were (1) Caregiver Mental Health, (2) The Information Gap and (3) The Need for Holistic Support. Mental health difficulties were reported, particularly around the period of diagnosis. Priority needs included the provision of clear information about the diagnosis and services offered, opportunities to forge peer support networks and for services across the community to collaborate.

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Conclusions: The delivery of health services for CYP with neurodisability should encompass the broad needs of the family as well as meeting the clinical needs of the CYP.

KEYWORDS

caregivers, cerebral palsy, child disability, community-based interventions, complex neurodisability, family, groups

1 | BACKGROUND

Neurodisability refers to a group of long-term health conditions, either from birth or acquired, that describe functional limitations due to impairments of the brain and/or the neuromuscular system (Morris et al., 2013). Neurodisability is said to be complex when the child or young person experiences physical/motor impairments alongside cognitive, communication, educational and social needs, which requires complex packages of multidisciplinary care (The National Confidential Enquiry into Patient Outcome and Death, 2018). The diverse comorbidities that accompany such a diagnosis result in increased health service needs, particularly in those with more severe physical challenges (Carter et al., 2021).

Cerebral palsy, an exemplar complex neurodisability condition, is the most common cause of childhood physical disabilities globally, affecting 1.6 per 1000 live births in high-income countries and an estimated 3.4 per 1000 in low- and middle-income countries (McIntyre et al., 2022). Cerebral palsy is an umbrella term used when describing irreversible, non-progressive injuries to the foetal or infant's brain. Children and young people (CYP) with cerebral palsy present with multiple health, educational and social challenges (National Institute for Health and Care Excellence, 2017) and resultant increased healthcare needs and utilisation (Berry et al., 2012; Meehan et al., 2017).

Caregivers of CYP with complex neurodisability can experience adverse health outcomes, for example, mental health and physical difficulties, which may result in higher levels of stress, anxiety, depression, pain, chronic diseases, financial instability, and reduced quality of life (QoL) (Pousada et al., 2013). In order to address the complex needs of the caregivers, healthcare professionals (HCPs) supporting CYP with complex neurodisability are encouraged to work in partnership with caregivers (Hayles et al., 2015; Prest et al., 2022). Multifaceted family-centred interventions can positively influence the well-being of caregivers by providing practical and social support for the child or young person and their caregivers (Prest et al., 2022). Peer support is also recommended for caregivers, which allows for opportunities to learn from others' experiences, group problem-solve and discuss everyday issues (Kingsnorth et al., 2011; Law et al., 2001; Shilling et al., 2013).

In the UK, guidelines from the National Institute of Health and Care Excellence (NICE) state that caregivers of CYP with cerebral palsy require extensive support and up-to-date information about cerebral palsy and services, particularly around the time of diagnosis (National Institute for Health and Care Excellence, 2017). Studies

exploring caregivers' experiences of accessing healthcare services for CYP with complex disabilities indicate that the provision of emotional, social and informational support, or lack thereof, was as important as the medical aspect of care (Anderson et al., 2013; Bellin et al., 2011; Campbell et al., 2021; Lindsay et al., 2012). For example, when accessing rehabilitation services, parents of CYP with cerebral palsy across low- and high-income country contexts expressed a desire for information on understanding terms relating to cerebral palsy and how best to support their child's development (Jindal et al., 2017).

However, there remains an implementation gap as caregivers continue to report difficulties in accessing information from health services about how to connect with other families (Anderson et al., 2013; Bellin et al., 2011; Kiernan et al., 2020; Liptak et al., 2006). They also report difficulties accessing holistic, family-centred support within the National Health Service (NHS) in the UK (The National Confidential Enquiry into Patient Outcome and Death, 2018). Better coordination of health services is recommended for families of children with complex neurodisability to reduce parents' experiences of repetitive support or lack of support (Kiernan et al., 2020). This is particularly poignant for ethnic minorities in the UK who face health inequalities in accessing hospital services and report poorer patient experience compared with majority white populations (Nazroo et al., 2009; Raleigh, 2021).

To begin addressing this implementation gap (The National Confidential Enquiry into Patient Outcome and Death, 2018), we reviewed interventions that might be suitable for parents/caregivers of children with complex neurodisability in the UK (Heys et al., 2020; Wilson et al., 2019). From this review, we identified the **Ubuntu model** as a potential intervention that could be adapted to the UK context. "Ubuntu" is a broadly pan-African term that means a sense of togetherness. It is a community-based participatory caregiver training programme that was adapted from a training resource called "Hambisela" in South Africa (van Aswegen et al., 2019). "Ubuntu" groups have been developed, tested and successfully implemented in resource-limited settings but holds potential for families in the UK, particularly in areas of high deprivation and ethnic diversity. The modular, facilitated intervention is comprehensive in that it aims to promote inclusion and participation for the child with complex neurodisability in the community, to maximise the child's health and development, to empower caregivers through information sharing and peer support, to address stigma, and to promote the human rights of children with disabilities (Tann et al., 2021). These holistic aims align with the WHO's social determinants of health framework and the RAND

“Future of Health” report in that social outcomes are considered as measures of improved health (Corbett et al., 2018; World Health Organization, 2010). The original programme has already been adapted for specific populations namely “Baby Ubuntu” for young children 0–3 years of age, and “Juntos” for children with Congenital Zika Syndrome in Brazil and Colombia. Evaluations of these programmes demonstrated improvements in parental confidence and self-efficacy, as well as improved QoL for the child or young person and their families (Duttine et al., 2022; Sadoo et al., 2022; Smythe et al., 2021; Zuurmond et al., 2018).

We conducted formative research to explore the suitability of adapting the “Ubuntu” programme to a UK context. Our aim was to test the feasibility and acceptability of the concept and content of the Ubuntu programme among caregivers and HCPs, in order to inform decisions regarding the nature and extent of any future adaptation within a UK setting. This forms part of the first step of the ADAPT framework for adapting complex interventions to new contexts and health systems (Moore et al., 2021). In exploring the anticipated acceptability of the programme, we garnered rich insights from caregivers and HCPs on the perceived needs and service gaps among caregivers of CYP with neurodisability in this context, alongside an understanding of their caregiving journeys. These findings are the focus of this current paper.

This is the first of two formative papers; the second will describe caregivers and HCPs' perspectives on the feasibility and acceptability of the concept of the ‘Ubuntu’ programme.

2 | SETTING

This was a UK-based study with caregivers accessing support for their children from HCPs in an NHS community setting. The NHS is a publicly funded healthcare service for residents of the UK and is free at the point of use. It is currently facing a workforce crisis, which has worsened throughout the COVID-19 pandemic (The King's Fund, 2022). This study was based in Newham, East London, an exemplar ethnically diverse London borough. Newham has the lowest proportion of first-language English speakers across England and Wales (Aston-Mansfield, 2017) and an estimated 52% of children live in poverty, higher than any other London borough (Trust for London, 2020). Adults in Newham experience a significantly higher prevalence of poor mental and physical health, as well as higher service use compared with the rest of the UK (Pevalin, 2007).

3 | METHODS

We conducted two rounds of semi-structured interviews between January and April 2021 with caregivers of children with complex neurodisability and HCPs. The first round explored the feasibility and acceptability of the overall concept of the Ubuntu programme (e.g., ethos, content and procedures) [S1]; and the second, focused on potential areas for adaptation (e.g., delivery mechanisms, content and

resources) [S2]. Topic guides were informed by intervention science frameworks, namely the Theoretical Framework of Acceptability (TFA) and Bowen's feasibility framework (Bowen et al., 2009; Sekhon et al., 2017).

Inevitably caregivers situated their responses to probing on the appropriateness of the programme within their lived experience, which generated rich insights into their caregiving journeys, navigation of health services, and perceived service gaps. We report the results from those analyses here as the first of two papers from this formative phase. A second paper (in progress) will report on the feasibility and acceptability of the programme concept.

Participants were eligible if they were the adult caregiver of a child or young person with a diagnosed complex neurodisability, aged 18 years or younger and resided in Newham, East London.

We adopted a purposive sampling approach to increase the likelihood of capturing a range of perspectives and experiences (Palinkas et al., 2015). The assumption was that the age of the child or young person, severity of neurodisability as well as the caregiver's ethnic and linguistic background may all be important factors shaping parents/caregivers needs, and the perceived acceptability and feasibility of the proposed Ubuntu programme.

We identified 45 potential participants from clinical lists. All 45 were contacted by a junior doctor, of whom 20 agreed to be contacted by a researcher and eight agreed to participate in the study. A second round of recruitment through parent/carer forums and contacting non-responders resulted in a further eight participants. In total, 16 caregivers consented to participate, 12 attended the first round and nine attended both rounds. Reasons for declining included limited time, moving out of borough, and competing child-care needs.

To increase ethnic and linguistic diversity of the recruitment of participants, it was made clear that translators could be available if English was not their first language. Translating services were used for the initial clinician recruitment calls, however there were a few instances where a translator was not available.

We aimed to recruit HCPs from a range of disciplines. A general recruitment email was sent out to HCPs providing care to CYP with complex neurodisability in Newham. The researcher subsequently contacted specific HCPs to allow for a variety of perspectives, particularly from those professions who may be involved in the delivery of an adapted “Ubuntu” intervention. Seven HCPs responded and of these, six agreed to participate and attended the first round of interviews, and four of the six HCPs attended both rounds.

All participants provided informed consent via an online form. One female researcher (IV) conducted all interviews remotely via Microsoft Teams because of COVID-19 restrictions (Manikam et al., 2021). The researcher is Greek Cypriot and a trained clinical psychologist. The interviews were video-recorded, transcribed verbatim and anonymised. Some participants requested the support of family members to assist with translation. A short questionnaire was used to collect demographic information before the interview. Interviews lasted approximately 1 hour, and there was only a short gap between

the first and second rounds of interviews to reduce the chance of disengagement.

Our analytical approach is broadly situated within a social constructionism paradigm, which assumes that human experiences are shaped by the societal context in which people are positioned, including language, culture, and their perceived sense of power (Burr, 2015). We conducted an inductive thematic analysis (Braun & Clarke, 2006). IV and SLJ read all transcripts ($n = 18$) to familiarise themselves with the data before coding them to create an initial coding framework, from which emergent themes and sub-themes were generated. These transcripts were then coded by a third researcher (KP), and the coding framework was further developed and refined. MH, EW and KP met to discuss coding labels and definitions. An additional meeting was held with EW and KP to discuss the final themes, sub-themes, analytical conclusions and to come to a consensus if there were any disagreements (Boyatzis, 1998). We used NVivo software (Version 20) for data management and analysis.

Patient and Public Involvement was incorporated in the formative stages of the study. Local clinicians consulted eight parents/caregivers in the acute and community clinical services in Newham to identify unmet needs and gaps in service provision, which informed the study protocol and grant application. Difficulties highlighted included navigating the health, educational and social care systems, a lack of clear communication and contact with health professionals particularly in the early staged post diagnosis, and a sense of isolation and lack of preparedness for having a child or young person with a complex neurodisability. A workshop was also held for parents/caregivers to provide feedback on patient-facing materials, procedures and to give advice on recruitment.

Ethics approval was provided from the UK Health Research Authority (ref 20/YH/0311).

4 | RESULTS

4.1 | Participant characteristics

Demographic information was collected (See Tables 1, 2 and 3). Caregivers' ages ranged from 31 to 42 years, with their children's ages ranging from 2 to 15 years. Most of the caregivers were mothers from ethnic minority groups, with variations in types of accommodation, employment and state benefits received. Two participants did not

TABLE 1 Participant demographic information: healthcare professionals.

Healthcare professional disciplines	$n = 6$
Health visitor	2
Occupational therapist	1
Paediatrician	1
Physiotherapist	1
Speech and language therapist	1

complete the demographic questionnaire. Demographic data was collected for the CYP whose caregivers consented to share their information ($n = 8$).

TABLE 2 Participant demographic information: parents and caregivers.

Demographic information of parents and caregivers	$n = 12$
Caregiver's age, range (mean)	31–42 (38) years
Gender	
Female	10
Male	2
Marital status	
Single, never married	3
Married, or in a domestic partnership	7
Unknown	2
Ethnic group	
Any White background	4
Afro-Caribbean	2
Pakistani	3
Bangladeshi	1
Unknown	2
Type of accommodation	
Flat/apartment/maisonette	5
House/bungalow	5
Unknown	2
Own or rent accommodation	
Rents	6
Owens	4
Unknown	2
Number of biological children living with caregivers, range (mean)	1–4 (2.4)
Highest qualification	
GCSE/O-level equivalent	4
Bachelor's degree	5
Master's degree	1
Unknown	2
Employment	
Part-time paid employment	2
Full-time paid employment	3
Unpaid or voluntary work including looking after family	5
Unknown	2
State benefits received	
Disability living allowance	9
Motability scheme	2
Carer's allowance	5
Child support	1
Universal credit	5
Unknown	2

TABLE 3 Participant demographic information: children and young people.

Demographic information of children and young people	n = 8
Age, range (mean)	2–15 (8) years
Gender	
Female	1
Male	7
Diagnosis	
Cerebral palsy	7
Other neurodisability	1
GMFCS ^a	
I	1
II	1
III	1
IV	1
V	1
Unknown	3

^aGMFCS: Gross Motor Function Classification System records a child's functional level of movement (Palisano et al., 1997). These data were only available for five of the children and young people.

4.2 | Themes

Three themes were identified that related to the aim of understanding caregivers' experiences and unmet needs. These were (1) Caregiver Mental Health, (2) The Information Gap and (3) The Need for Holistic Support.

4.3 | Caregiver mental health

Several factors were described by caregivers and HCPs as adversely impacting upon caregiver mental health, namely: receipt of diagnosis; the overwhelming number of tasks required of them; feeding; concern about the future; transition to school; and feelings of isolation. Conversely adequate support, knowledge and early diagnosis were reported by two participants as positively impacting on their mental health.

Many caregivers described feelings of anxiety and low mood, particularly around the period of diagnosis. These reported difficulties with mental health were irrespective of the severity of their child's diagnosis or the caregiver characteristics.

I think being a parent is overwhelming ... but I think when you add this into the mix when you weren't expecting it, because most of us don't expect it. It is overwhelming. I've definitely had periods of feeling low and feeling like a failure and then wanting to give up.

-C13

All participants reported their own or their partner's initial denial over their child's diagnosis. This experience further influenced their mental health, often resulting in periods of anxiety and depression.

I did have a bit of a small breakdown after about a month when my husband accepted what had happened to my son. I think I let my guard down knowing that and then it kind of hit me all in one go. I had a little bit of a panic attack once.

-C16

They reported feeling powerless within the process and overwhelmed by the many tasks required of them. Caregivers described the burden of appointments for their child, including difficulty keeping track of them all and the overloading of information. A few mentioned that they had no time for themselves.

Multiple caregivers discussed feeding issues as a particular trigger for anxiety as part of the overall pressure felt in caring for their child. One parent reported feeling worried about leaving the house as they did not know whether places would be accessible for their child.

Worrying about the future was another aspect of anxiety that caregivers frequently mentioned. One caregiver reported feeling powerless as they did not know what to expect and what their child might be able to do. Other caregivers expressed worry about their child's plans for schooling and becoming adults.

I'm worried a lot about college ... Now everything is okay, but when he finishes school and he has to go to college and start living his adult life, I'm really worried and I don't know how everything will be. It's basically something new for me and it worries me a lot.

-C11

One HCP confirmed the above by reporting their observations of caregivers feeling anxious about sending their child to school and transitioning between different education environments.

From working with families, [the education side of things] is always quite anxiety provoking. The whole way through transitioning into different education systems and making sure that the child's at the right school and [receiving] the right opportunities in school. And I think that's quite hard for some families to get their head around.

-H4

As part of the impact on caregivers' mental health, many described how their friends and family had difficulty understanding their situations. Caregivers reported struggling to socialise with other families because of their child's barriers to play. They discussed having no prior reference point to how to interact with a disabled child, or not knowing what to say to the parent/caregiver.

In my social group I am the only one with a child with special needs. So even when I try to speak to some friends, they'll never understand. And they always look at the brighter side of everything, because he's always so happy. But then they don't see when we have to do physio every day, when I'm struggling feeding him. They don't see the dark side of it. They just see the happy-go-lucky baby.

-C3

The varying difficulties reported above resulted in parents feeling isolated and that their support networks could not understand them. This sentiment of isolation was shared amongst many of the participants, which was reported to be compounded by the lack of support and information provided by HCPs.

Isolation is such a big theme amongst parents and carers with kids with disabilities.

-C1

One caregiver reported a markedly different experience. They described themselves and their partner as the 'luckiest parents' as they received an early diagnosis and increased support and advice from doctors and allied health professionals. They reported that this increased support assisted them in their acceptance of the diagnosis. Another parent described how their anxiety was reduced when HCPs provided them with information about what to expect for certain milestones and activities. -C11.

I think that anxiety and depression is such a major thing amongst carer parents that if we are given enough information to help us just calm down, you would find that the rates of depression anxiety would lower a little bit as well.

-C1

4.4 | The information gap

A prominent finding was that caregivers expressed a lack of knowledge about their child's condition, associated co-morbidities and the accompanying services available, along with frustration with the over-use of medical jargon by HCPs. They described seeking information and assurance from sources outside of healthcare.

Caregivers had varying experiences of how involved HCPs were in the initial stages of their journey, but many reported feeling disappointed by the system.

I felt a bit let down by the medical system. I found out that my son probably has cerebral palsy before I was told because the doctors didn't give me any information ... I felt let down by NHS staff when I initially got the diagnosis. I was very angry and

frustrated. In the beginning, the first NHS staff that kind of made me feel better was my physiotherapist a few months later.

- C16

Caregivers reported difficulties understanding what the diagnosis of cerebral palsy would mean for their child, along with accompanying co-morbidities such as feeding and communication difficulties, bowel problems or epilepsy.

We were sort of thrown the word cerebral palsy, there wasn't ever an explanation. I wasn't sent any information packs... I was [in my 20s] at the time, so I had no idea what was going on and you can feel really lost.

-C1

A few caregivers described various supports available to families; however, there was often a lack of knowledge about how to access them. This included a lack of awareness of assistive devices and equipment availability, financial support such as carers' allowance, and support groups. From the caregivers' perspective, it was sometimes difficult to understand the different roles of the various HCPs.

There is support out there, but not a lot of people know where to look for the support, because I didn't, and I still don't know.

-C3

One HCP commented that information about the local offer for families could be challenging to find.

I think the local offer is not good in Newham compared to other areas and it's hard to find information in it. I struggled to find information myself when I was looking for things.

- H1

One of the most frequently mentioned difficulties was the complex terminology that caregivers had to dissect after their child was diagnosed with cerebral palsy. This included medical jargon and acronyms, such as the commonly used Gross Motor Functioning Classification System (GMFCS), (Palisano et al., 1997) levels. Language barriers made this particularly challenging. Caregivers expressed concern that there was not enough time during doctors' appointments to deal with all of their questions, particularly in the period just after diagnosis. One parent reportedly felt more relaxed if they could bring someone else to the appointment.

I just went on to some parent forums because lots of the NHS staff I found to be more medical. And there was lots of jargon that I didn't understand and that

depresses me a bit because I'm not a stupid person. I then just joined forums and started talking to parents as I just didn't know what else to do.

-C13

Because of the gaps in knowledge described above, caregivers frequently conducted independent research. Sources of information included the internet, charities, and parent groups. Concerns were raised about processing the volume of information available. Caregivers reported feeling fearful of their child's prognosis when seeing children with severe difficulties online.

I had no idea what was going on and you can feel really lost because you're told that they have a condition and then the problem is when you go on the Internet, there is such a vast world [of information] ... So I'm seeing cerebral palsy people [who are not] walking, in wheelchairs and not feeding ... when you are a new parent or even a parent whose never had a child [with a] disability before, I feel as though you need to be given proper information so that you're not running away with it yourself.

-C1

Some parents will actively tell you that they're looking on Google and others will say that they're not ready to do that

-H2

4.5 | The need for holistic support

All participants described the need to provide holistic and timely support for families with a child with complex neurodisability – both from the healthcare system and from the community.

Participants discussed the lack of communication between various departments who care for CYP with complex neurodisability. It was suggested that collaborative joint-working of HCPs in varying disciplines should be prioritised to streamline services for families. Caregivers described the need to seek support elsewhere, for example privately or in different countries. HCPs described the tension of a service under pressure, against a desire to do more to support families. Multiple caregivers raised concerns about the infrequency of appointments, and it was suggested that having a telephone number to call and speak to someone, would be welcome.

I was walking into [that first appointment] on my own. I have my little boy with me and when I left, I just sobbed because I had absolutely no idea that it was coming. And there was no support. There was nothing. The child's got cerebral palsy. Not even a telephone number of a support group. Just absolute darkness.

And I was very low for a long while until I dragged myself up because I didn't know what to do.

-C13

All participants raised the need for individualised support for children with complex neurodisability, particularly concerning feeding, positioning, home visits and condition-specific information. One HCP described how services were often aimed at different diagnoses and that there was a clear need for further individualised support for families with CYP with cerebral palsy.

A lot of these coaching parental support things are around, but for autism and behavioural issues, not for children with cerebral palsy, so that's what's missing. Their needs are very, very different and that needs to be addressed in a different way

-H4

Caregivers stated the need for further support from the community, and to connect with others who have lived experience. Most caregivers reported that it was important to hear stories and learn from others in similar situations, even though each family's needs are unique. This connection and learning reportedly reduced feelings of isolation and positively influenced their mental health.

I think the group delivery is quite important because, especially at the beginning, you feel like you are the only person who is going through it, so it's nice to hear when there's other people coming in with similar backgrounds and stories. Part of this whole thing is you can feel really isolated so even something as simple as doing a group exercise, I think psychologically will do something.

-C1

A few caregivers expressed a desire to help other families who were earlier on in their journeys, to assist in alleviating worries. One participant mentioned the importance of having adult role models who have a diagnosis of cerebral palsy. It was suggested that involving families or people with cerebral palsy in the training workshops would be valuable.

When I first heard the word cerebral palsy, I didn't know what it was, I didn't know anything about it, it was so new to me. And thankfully when I read a story, exactly what I'm going to be producing as well, it helped me to understand.

-C5

Along with the support required from health services and groups, a few caregivers expressed the need for further support from the wider community and schools. Both caregivers and HCPs described the benefits of extending educational support and awareness to

friends and family members, along with the wider community, with the overall aim of decreasing stigma and improving understanding.

I think it would also be helpful [to invite] your extended family [to the groups] ... it's sometimes important for your circle of family and friends to understand what it is that you're going through on a day-to-day basis.

-C14

Once people understand what disability is all about, maybe what cerebral palsy is all about, they don't go around judging and looking.

-H6

Multiple caregivers expressed a desire for support and advice from healthcare services about the schooling process and how to access funding. Parents/caregivers discussed the need for Special Educational Needs Co-ordinators (SENCOs) to have specific training, to improve their understanding of the needs of CYP with complex neurodisability. It was suggested that schools in the area, both specialist and mainstream, could be linked into the programme. Finally, caregivers described the need for more leisure opportunities for their children, for example sports clubs, to improve overall participation in the community.

5 | DISCUSSION

This qualitative study explored the needs of those caring for CYP with complex neurodisability in a diverse urban setting. To our knowledge, it is one of a handful of studies exploring these factors in such a diverse population (Akbar & Woods, 2019; Arfa et al., 2020; Khanlou et al., 2015). We report significant unmet needs, resulting in subsequent adverse impacts on caregiver mental health, consistent with studies in upper-middle and high-income contexts (Arfa et al., 2020; Gilson et al., 2018; Hayles et al., 2015; Pousada et al., 2013; Rosenbaum & Novak-Pavlic, 2021). Research in the field of child neurodisability emphasises the importance of supporting families as a whole (Rosenbaum & Novak-Pavlic, 2021), however, how to provide this within the constraints of a publicly-funded healthcare system remains problematic. Our data suggest a community-based intervention, such as the “Ubuntu” model, may meet some of these unmet needs and provide family-centred support.

We define unmet needs in healthcare to broadly cover non-use, delayed use and sub-optimal use of health services, which can have detrimental impacts to the wellbeing of certain populations (Smith & Connolly, 2020). Caregivers' unmet needs in this study included the need for support for their mental health, the need to be empowered with knowledge and skills, and the need for services to be better coordinated to enhance the overall care. HCPs identified gaps in service provision for individualised support for CYP with cerebral palsy and their families.

One of the ways in which caregivers' mental health was impacted by having a child or young person with a complex neurodisability, was through the difficulties in managing multiple appointments from a variety of healthcare services. McCann et al. (2012) conducted a systematic review of the daily patterns of time use for children with complex needs and found that caregivers spent considerable time engaged in healthcare-related activities for their children, placing a significant caregiving burden on them. With relation to mental health, the concept of ‘future’ was mentioned frequently in this study as caregivers expressed anxiety about the unknown potential of their child's development. Rosenbaum and Gorter (2012) place an important emphasis on HCPs keeping a child's future in mind when working with families, without ignoring present concerns. An implication for practice might be for HCPs to incorporate discussions around future into consultations, as this might have an impact on caregiver mental health.

Previous studies conducted in upper-middle and high-income contexts have reported a link between poor mental health, social isolation, exclusion, and stigma and the time-consuming, continuous tasks required of caregivers (Breitkreuz et al., 2014; Khanlou et al., 2017; Luijckx et al., 2017; Resch et al., 2010; Rodrigues et al., 2019). Caregivers in this study reported feeling isolated and alone in their difficulties, with their support networks not able to understand their struggles. This experience is mirrored in a variety of contexts and demonstrates the importance of forging support networks for caregivers. It should not be assumed that a caregivers' ability to cope is correlated with the nature or severity of their child or young person's diagnosis, which is supported by previous studies (Parkes et al., 2011; Skok et al., 2006). Caregivers in this study expressed a need to connect with others in similar situations. Not only does this provide opportunities for a shared social identity which can have a positive impact on health and wellbeing and bring a sense of belonging (Haslam et al., 2009), but it also provides opportunities for mutual support. Reciprocity offered in social support was important to participants, which is echoed in previous literature (Reid et al., 2011; Shilling et al., 2013). A participatory group programme such as “Ubuntu” is uniquely positioned to introduce parents/caregivers in similar situations to allow for the development of support networks, reducing feelings of isolation and allowing for support to be reciprocal.

NICE guidelines recommend the provision of timely and appropriate information for families of children with cerebral palsy, particularly during the period around diagnosis (National Institute for Health and Care Excellence, 2017). Multiple caregivers in this study reported the need for further information and individualised support about their child's condition. This is echoed by previous studies, particularly in relation to parents finding it challenging to receive up-to-date information and support (Arfa et al., 2020; © Care Quality Commission, 2012; Kiernan et al., 2020). It is also recommended that the support provided for families of children with cerebral palsy be individualised, as a ‘one-size-fits-all’ approach is not appropriate for this population (Hayles et al., 2015; Terwiel et al., 2017). Caregivers further described the need for support in understanding

complex medical terminology. Parents from a variety of contexts have raised similar concerns (Jindal et al., 2017; Liptak et al., 2006) emphasising the need for clear communication of medical terms, particularly considering language and culture (Arfa et al., 2020). One of the aims of the “Ubuntu” programme is to provide clear, jargon-free information and to equip parents/caregivers with the skills and confidence to seek out appropriate information and support. By improving their health literacy and patient activation, there may be improvement in the communication between parents/caregivers and HCPs.

A key finding of this study was the need to improve co-ordination of services in healthcare, schools and in communities, particularly during significant transition points. A review into the quality of care provided for patients with chronic neurodisability in the UK (The National Confidential Enquiry into Patient Outcome and Death, 2018) emphasised the critical importance of improving communication between HCPs and families, as well as streamlining the co-ordination of care amongst the varying multi-disciplinary teams. Previous studies have also emphasised how crucial it is to improve co-ordination of the varying services that aim to meet the multi-faceted needs of these families (Kiernan et al., 2020).

6 | STRENGTHS AND LIMITATIONS

This study had several strengths, such as involving both service users and healthcare providers, allowing for multiple perspectives to be gained. Despite a small sample size, there was variation in caregiver and child characteristics, leading to rich data generation. The interviewer's (IV) nationality, particularly being an immigrant, allowed rapport to be built quickly, while her clinical psychology training helped her discuss sensitive topics. Some interviews were conducted with family members acting as interpreters, which could lead to a loss of nuance and privacy, however allowing participants to answer in their first language is a strength. Some caregivers were not provided with study information because of a lack of interpreters during recruitment, meaning data from underrepresented families may be missing. Finally, only one child did not have a diagnosis of cerebral palsy, raising questions about combining children with different neurodisability conditions in a group.

The COVID-19 pandemic affected recruitment and data collection, with remote collection being more convenient for some, but challenging for others because of privacy or digital access. Three participants did not attend online interviews, and those who declined to participate cited time and childcare pressures, possibly excluding those with the greatest caregiving burden.

Techniques to enhance trustworthiness (Lincoln & Guba, 1985) in this qualitative study included member checking where participants were invited to a workshop to discuss the preliminary findings, researcher triangulation and peer debriefing during data analysis, and prolonged engagement in the setting by the researcher who conducted the interviews (IV). Thick description was used to provide information about the setting, which may allow for transferability to

other ethnically diverse urban settings, with similar pressures on NHS health and social service provision.

7 | CONCLUSION

This study demonstrated the crucial importance of focusing on caregivers' mental health as well as empowering them with knowledge, whilst at the same time streamlining services provided by health and social care to better support families of CYP with neurodisability. The delivery of health services in diverse and socially deprived urban settings should encompass the broad needs of the family, by providing holistic care with clear and up-to-date information, facilitating the forging of peer support networks, as well as meeting the biomedical needs of the CYP. Many of these needs have repeatedly been reported by caregivers globally, however health inequalities exacerbate these problems, and the implementation of family-centred care remains a huge challenge. Although the findings may not be novel, the proposed solution of co-adapting the “Ubuntu” programme is a new and innovative approach to implementing family-centred care in order to meet the needs of families with a child with complex neurodisability. The findings in this study have begun to inform further adaptation work. This process has been strengthened by gaining in-depth insight into the context of the caregivers and families.

AUTHOR CONTRIBUTIONS

EW, IV, SA, HK and MH conceptualised the paper, and ML, CM, CT, PH, HK and MH were involved in funding acquisition. The methodology was developed by EW, IV, SA, ML, CM, CT, PH, HK and MH. Data was collected by IV and analysed by KP, EW, IV, SLJ and MH. The project administration was undertaken by IV, SA and MH, with EW and MH supervising. KP, EW and MH drafted the original manuscript and all authors contributed to reviewing and editing it.

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CONFLICT OF INTEREST STATEMENT

None declared.

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