How does one nursery setting support Somali parents in early years with neurodevelopment disorders?

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Abstract

This research study aims to gain an understanding of how one setting support Somali parents with children with Neurodevelopment Developmental disorders living in Birmingham. It investigated the perception of Neurodevelopment Developmental disorders within the Somali community, the cultural sigma Somali parents may face, and strategies settings use to support Somali parents. The sampling size for the semi-structured interviews consisted of 4 practitioners working closely with Somali families with children with Neurodevelopment Developmental disorders, and the focus group discussion involved five Somali parents with children with Neurodevelopment Developmental disorders. Two themes were identified using thematic analysis: the cultural perception of NDD and strategies to supporting Somali parents. The key findings suggest the setting faces cultural and communication barriers when supporting Somali parents with children with Neurodevelopment Developmental disorders and how the sociocultural challenges Somali parents experience within the Somali community can affect how Somali parents seek help in early years setting.

Key words: NDD, Somali community, perceptions, challenges, culture, lack of awareness

Common Abbreviations

Neurodevelopmental Disorders - **NDD**

Autism Spectrum Disorder- **ASD**

Attention Deficit Hyperactivity Disorder- **ADHD**

Contents

Introduction

Neurodevelopment Developmental disorders (NDD) are associated with conditions affecting the neural functions within the brain that affect children's social, emotional, academic, and behavioural problems (American Psychiatric Association 2016, p.1). Shevell *et al*. (2003, p.367) and Blackburn *et al.* (2012, p.2) highlight NDD affects three percent of children globally and is estimated to affect three to four percent of children in the UK. Barnevil-Olsson *et al.,* (2008), Iqbal *et al.* (2016) and Baraza (2019) research studies revealed the prevalence of NDD in the Somali community is estimated to be three times higher than other ethnic minorities. However, the cause for a higher prevalence of NDD in the Somali community is yet unknown. Nevertheless, research findings by Fox *et al*. (2019) and Abdi *et al.* (2015) recognised cultural stigma, lack of awareness of NDD and the perception of mental health prevents Somali parents from recognising NDD and seeking and accepting help. This highlights there may be difficulties and challenges Somali families face in understanding and accepting support provided by early years settings.

This research study aims to investigate the cultural stigmas that NDD parents experience within the Somali community and explore how one setting implements support to Somali parents with children with NDD. Thus, the key question for this study is: How does one nursery setting support Somali parents in early years with neurodevelopment disorders? Three subsidiary questions derived from the secondary research and literature to highlight gaps in current literature:

1) What types of Neurodevelopment disorders are seen in the Somali community?

2) What barriers do settings face when supporting Somali parents with children with neurodevelopment?
3) What strategies can settings provide to support Somali parents with children with neurodevelopment disorders, specifically Autism Spectrum Disorder (ASD) and Attention Deficit Hyperactive Disorder (ADHD)?

This research study utilised interpretive qualitative paradigm and applied several methods of data collection, which ensured triangulation, reliability, and validity (Glesne and Peshkin, 1992, p.8; Cohen *et al.*, 2017, p,289; Heale and Forbes, 2013). The research study took place in an early year setting, located in Birmingham, and used to non-purposive sampling to recruit participants (Parton, 1990, p.169). To understand the perception of NDD within the Somali community, five Somali parents with children with NDD participated in a focus group and four nursery practitioners working closely with Somali parents were also employed for a semi-structured interviews to investigate the challenges settings face when supporting Somali parents with children with NDD (Cohen, 2017, p.267).

The researcher worked closely within the Somali community in London for several years and directly experienced the difficulties Somali families with children with NDD experience navigating the education system. This inspired the researcher to review literature on Somali parents in early years education with similar experiences. The researcher discovered the Somali community is underrepresented in research in early education in general and little research is available regarding the difficulties in neurodevelopmental research within the Somali community, in particular, the experiences, perceptions and attitudes towards disabilities such as ASD and ADHD (Fox *et al.*, 2017; Selman *et al.,* 2019). Thus, this research aims to gain an

understanding of how NDD is perceived and understood within the Somali community and contribute to the limited research available surrounding neurodevelopment disorders with the Somali community.

The next chapter presents the literature review. The methodology chapter is the third chapter, the fourth chapter will discuss the findings and analysis and finally, a conclusion will draw up the key findings.

Literature Review

Introduction

A literature review can be defined as a critical summary and evaluation of available materials within a specific chosen topic (Blaxter *et al.*, 2006, p.123; Mukherji and Albon (2010, p.201). Blumberg *et al.* (2005, p.11) defines a literature review as an appropriate summary of previous work, with an added interpretation presenting a brief overview of the existing literature of the chosen topic, whilst also including ones' own personal analysis and perspective of the matter. However, Schwarz *et al.* (2006) argue a literature review is not just an overview of literature, but rather a critical analysis of the existing literature on the given topic as well as supporting the research goal of the study. Thus, a literature review can be used to identify gaps to critical knowledge in a chosen topic to determine where further research is needed (Webster and Watson 2002). A literature review allows researchers to understand the current state of knowledge on a research topic and identify further research needs (Denscombe, 2003, p.195). Therefore, this literature review will provide a comprehensive overview of previous research in regard to early years settings supporting Somali parents with children with NDD. It will explore the different types of NDD seen in the Somali community, the barriers settings face, and the strategies settings provide when supporting Somali parents with children with NDD.

Limitation to existing literature

This literature review will provide better understanding of NDD and how it affects the Somali community. However, there is a vast amount of literature available regarding ASD in the Somali community relating to the lack of awareness has been researched and documented. Although ASD is not a specific area of interest for this study, most of the literature used is related to ASD within the Somali community. Furthermore, little research is available regarding the different perceptions of NDD, and how they are diagnosed and managed within the Somali community, in order for settings to provide support for Somali parents with children with NDD.

Types of neurodevelopment seen in the Somali community

NDDs are disabilities referred to as a collection of various conditions that stem from abnormal development of the central nervous system and typically present themselves during infancy or early childhood (Abdullahi *et al*., 2018, p.30). NDDs are associated with conditions relating to neural functions within the brain that affect children's personal, social, academic, occupational functions and behavioural problems (American Psychiatric Association, 2016, p.1). Globally, it is estimated one in three percent of children are commonly affected by NDD (Shevell *et al*., 2003, p.367). Furthermore, it is estimated three to four percent of children in the UK have NDD (Blackburn *et al.,* 2012, p.2). Research conducted by Russell *et al*. (2013) highlights the most prevalent types NDD are ASD and ADHD.

ASD is a NDD that is characterised by the deficits in social communication, as well as the presence of restricted interest of repetitive behaviour (Lauristen, 2013, p.37; American Psychiatric association, 2013). Research conducted by Baird *et al.* (2006) estimates that ASD impacts one in one hundred and sixty children in the UK, whereas

a population-based study in Sweden estimated that the prevalence of ASD in the Somali community is three times higher in children than other ethnic groups (Barnevill-Ossson *et al*., 2008). Furthermore, Hassan (2012) found that Somali children in the UK are twice more likely to be given ASD Diagnosis compared to Black Caribbean and Black African backgrounds. This suggests that while both Barnevill-Osson *et al.* (2008) and Hassan (2012) finding's recognise the cause of high prevalence of ASD in the Somali community is unknown, it was acknowledged that immigrant communities benefit from access and support to ASD services. ADHD is a NDD which causes ongoing symptoms of inattention, hyperactivity, and impulsivity (National Institute Health and Care Excellence (NICE) guidance, 2019; Matte *et al*., 2015). The prevalence of ADHD is estimated to be affecting three to five percent of children in the UK (Newschaffer *et al.*, 2007; Brown *et al*. 2001; Polanczyk *et al*. 2007). However, Russell *et al.* (2013, p.31) argue that there is no UK health record that provides an exact count of children with an ADHD diagnosis. Furthermore, Rowland *et al.* (2002) highlights that there is little reliable research available regarding the prevalence of ADHD in different racial and ethnic groups. This suggests that the prevalence of ADHD in the Somali community is not clear in existing research.

In the Somali community, the prevalence of NDD is estimated to be three times higher than other ethnic minorities (Barnevil-Olsson *et al.,* 2008). Research conducted by Iqbal *et al.* (2016) estimated that the effects of NDD in Somalia is 3.25% higher than other African countries. Similarly, Baraza (2019) estimated that the number of children with NDD in the Somali community was significantly higher compared to non-Somali children. However, these studies do not specify children who have not yet been diagnosed with NDD, which could suggest that the statistics are not accurate. To date,

there are fourteen research studies available examining the prevalence of ASD in the Somali community. However, the findings do not identify the cause of higher prevalence of NDD within the Somali community (Barnevik-Olson *et al.*, 2008; Barnevik Olsson *et al.*, 2010; Leonard *et al.*, 2011; Leonard *et al.*, 2005; Becerra *et al.*, 2014; Kira *et al.*, 2012; Bolton *et al.,* 2014; Van *et al.,* 2013; Delobel-Ayoub *et al.*, 2015). Nevertheless, each research study revealed the prevalence of ASD within the Somali community is higher in comparison to other ethnic groups (Abdullahi *et al.*, 2017, p.31). This demonstrates that it is important for early years settings to ensure they are supporting Somali parents to bring awareness of NDD within the Somali community.

Barriers settings face when supporting Somali parents with children with NDD.

Internal stigma

Internal stigma is referred to as negative attitudes or beliefs that a member of a particular group may hold about others in the same ethnic group who may be perceived as different from social norms, which can lead to discrimination (Corrigan *et al.*, 2005; Corrigan and Watson, 2002, Corrigan *et al.*, 2006). There is a significant amount of research surrounding 'internal' stigma within the Somali community, which highlights many parents 'feel guilty, shame and fear', are forced to hide their children's disability and are 'blamed' for their child's disability (Fox *et al.*, 2017, p.308; Selman *et al.*, 2018). However, it is difficult to say whether this is due to the lack of NDD awareness within the Somali community or if it is due to cultural perceptions of mental disability as it is seen as being 'ill', (Abdi *et al.,* 2015). The Somali community believe

that any 'illness', specially symptoms of behaviour or mental health, can be cured with religious healing and would therefore stay away from seeking professional help (Antoniotto, 1984, Abdullahi, 2001, p.67). Somali parents are believed to be more sensitive to disability related stigma and tend to refrain from community social gatherings (Alakerrki, 2022, p.3). This suggests that it is necessary to bring awareness to NDD within the Somali community.

It is common for Somali parents with a mentally disabled child to be addressed or nicknamed by the community for the disability their child has due to cultural stigma. For instance, if a child has ASD, the parents will be nicknamed by their child's condition, meaning they would be referred to as 'the parent with the autistic child' (Helander, 1995, p.75). Research findings by Hussein *et al*. (2019) revealed that Somali parents felt that Somalis where 'quick to label' people who are 'different' within the community. This could lead to Somali parents being forced to hide their child's disability and delay seeking help. Furthermore, Thomas and Rushford, (2015, p.113) assert social and cultural knowledge of certain disabilities are limited in the Somali community which can lead to isolation. Additionally, Selman *et al.* (2018) highlight the cultural stigma surrounding NDD which prevents Somali parents from accessing services and also emphasises how the challenges associated with caring for children with NDD causes Somali parents to feel socially isolated. This shows that internal stigma surrounding mental disability in the Somali community is prominent and causes Somali parents to feel discriminated against and isolated.

<u>Lack of awareness</u>

Disability and disorders differ in different cultures. Stigma surrounding mental disabilities in the Somali community can lead to lack of acceptance and denial of certain disorders (Fox et al., 2017; Binder, 2012). In Western countries, NDDs such as ADHD and ASD are recognised as a disability (Zhang and Bennet, 2003). Whereas in the Somali community, ADHD and ASD are not recognised as NDDs (Kuenzil, 2012, p.18). This is due to the fact that there is no word in the Somali language for ASD and ADHD (Fox *et al.,* 2017). An explanation for these views could be due to physical symptoms of ASD and ADHD not always being visible, which could be linked to cultural beliefs surrounding NDD in the Somali community. For example, Schuchman and McDonald (2004) claim that Somali parents traditionally justify behaviours of ADHD as a consequence of spiritual causes or possession by evil spirits, which could be due to Somali parents' comprehension of ASD and ADHD symptoms, resulting in them feeling embarrassed and isolating themselves from social gatherings (dosReis *et al*., 2010). Similarly, Hussein *et al.* (2019) reported how Somali parents described behaviours of NDD as 'rudeness' and use language such as 'spoilt' and 'mental health problem'. Furthermore, while Sahuric *et al*. (2021) highlight that teachers reported symptoms of ADHD in migrant children, immigrant parents did not recognise those symptoms as ADHD. This highlights the cultural misconception and the lack of comprehension of ADHD symptoms within the Somali community, which could lead to delays in diagnosis. Perhaps the statistics of the prevalence of NDD could be higher if the Somali community had knowledge and understanding of NDD.

A research based in Somalia, conducted by Tomlinson and Abdi (2003), found the existence of traditional beliefs that disabilities such as ASD and ADHD are caused by 'demons', which makes it difficult for Somali parents to seek help. This leads to parents

receiving little sympathy from the community and extended families and may worry about family members criticising them for seeking help (Tomlinson and Abdi, 2003). On the other hand, Fox *et al.* (2018) found that religion and faith had a positive effect on Somali parents in accepting their child's diagnosis and receiving support, which highlights that religion plays a significant role in influencing Somali parents' views of NDD. Furthermore, a study conducted by Gary (2002) highlights the negative perceptions and stigma surrounding NDD by extended families can lead to parents feeling isolated and lonely. Additionally, mothers with NDD children reported that their children's fathers were uncomfortable with the diagnosis or resisted the diagnosis (Gary, 2002). This could be due to a general absence of physical symptoms and lack of misunderstanding of NDD within the Somali community, which could lead to family members finding it challenging to accept their child's diagnosis. Similarly, Selman *et al*. (2018) explained that some Somali parents with NDD children deliberately isolate themselves from their community to avoid having to explain their child's disability and behaviour when their child doesn't act according to social 'norms'. This highlights how Somali parents are forced into keep their child hidden from the community due to fear of stigma and lack of understanding of NDD within the community. Arguably, research shows Somali parents believe NDDs such as ASD and ADHD are caused by environmental changes, food, lack of vitamin D and vaccinations (Bettman *et al*., 2015; Miller-Gairy and Mofya, 2015; Wolf *et al.,* 2016). However, themes in available literature based on the Somali community highlights parents are hopeful and believe that NDDs can be cured. Somali parents believe children will grow out of NDDs and believe taking their children back to Somalia may help improve their diagnosis (Fox *et al*., 2017; Miller-Gairy and Mofya, 2015). This demonstrates the stigma associated

with NDD and the lack of awareness of hidden disabilities within the Somali community and disparities Somali parents face, which could lead them to delay or accept seeking help.

Language barrier

Language competence can affect a families' ability to utilise services provided by early years settings. In order for Somali parents to accept their child's NDD diagnosis, parents are required to understand what NDDs are, which requires parents to learn more about the diagnosis (Fox *et al.*, 2017). However, Deseking *et al.* (2011) highlights ethnic communities have varying levels of health literacy and may have difficulties understanding treatments for their child's NDD effectively. Furthermore, a qualitative study by Fox *et al.* (2017) highlights how Somali parents expressed frustrations in navigating the system and understanding the diagnosis process. Similarly, Khanlou *et al.* (2017) research study revealed that mothers found it difficult understanding information that was given to them relating to accessing support for their children. This led to immigrant parents expressing doubt that they would receive help from professionals. One parent expressed that parents need more respectful translators with knowledge about disability (Khanlou *et al.*, 2017). Likewise, Smith *et al.* (2023) identified that mothers felt that professionals did not keep them updated regarding their child's NDD development and communication was limited. This demonstrates problems relating to linguistic barriers can limit Somali parents accessing and understanding health and education services for their children with NDD.

In addition, research conducted by Miller-Gairy and Mofya (2015) identifies that limited English abilities prevented parents from fully engaging in conversations with their

providers regarding their child's disability. Khanlou *et al*. (2015, p.1842) explains that service providers recognise that communication is a key challenge when supporting immigrant families as mothers have difficulties accessing services and communicating. Alternatively, Smith *et al.* (2023) highlights that Somali parents with children with NDD felt that the school did not gain correct consent from them when referring their children due to their limited English. This suggests that Somali parents felt dismissed by the professionals at the school. Similarly, Khanlou *et al*. (2017) identified that parents struggled to understand terminologies hindered them from accessing services for their children with NDD. This highlights that Somali parents can be at a disadvantage in accessing services provided by early years settings due to language barriers.

Strategies settings provide when supporting Somali parents with children with NDD.

Parent partnership

Efficient parent partnership in early years settings can improve the outcomes for children with NDD. Practitioners play a central role in successfully supporting children's development through parent partnership (Robson, 2006). It is believed that promoting positive parent partnership improves parenting practices, parent-child relationships, decrease children's internal and external problems and improves parents' mental health (Stewart-Brown *et al*., 2004; Morgan *et al.,* 2012). Furthermore, Lilley (2019) believes that parent partnership involves good communication, together with trust and respect between the parents and practitioners. However, aside from 'good

communication' (Fox *et al.*, 2017), little research is available surrounding what constitutes to an effective partnership for Somali parents with NDD children. Early years settings should provide strategies when working in partnership with Somali parents. For example, settings can offer opportunities for Somali families to network and connect with other families in similar situations to avoid being isolated (Chan, 2011, p.71). When working in partnership with parents, professionals can support parents to obtain and build the essential abilities to ensure their children's needs are met (Bailey *et al.*, 2012; Bruder, 2010). Koegel *et al.* (2014) claimed that professionals can ensure parents gain the skills and confidence they need to manage and support their children's disability, which in turn helps decrease and prevent stress and anxiety for parents when working in partnership. Similarly, Suma *et al.* (2016) highlighted that professionals can equip parents with tools to support their children and strengthen the relationship between parents and children. This suggests that early years professionals can provide strategies to support Somali parents, which can result better outcomes for children with NDD (Kingdon and Gourd, 2014, p.14).

One strategy settings could explore when working in partnership with parents is finding ways to involve parent's cultures within educational settings, and connect community members to suitable services and supports them outside of the setting (Schultz *et al.*, 2016; Fox *et al.*, 2017; Hussein *et al.*, 2019., Selmam *et al.*, 2018). For example, settings can provide workshops for Somali parents to bring awareness and understanding of NDD. Research conducted by Rosenblatt (2018) identified that providing workshops and training that is specifically designed for Somali parents supported them to reduce stigma and increase NDD awareness within the community. Additionally, Selman *et al.* (2018) and Fox *et al.* (2017) both identified that Somali

parents benefited from structured training courses and support groups. DuBay *et al.* (2018) further mention that parents with children with NDD who avoided sharing their children's diagnosis benefited from support groups with other parents who are experiencing similar problems. On the other hand, a study conducted by Jagatheesan *et al.* (2010), findings suggests that some parents were uncomfortable talking about their feelings with groups of people who were at different levels of understanding. Similarly, Louong *et al.* (2009, p.227) revealed that immigrant parents did not benefit from support groups, and a mother expressed 'I did not want to hear about other people's problems, and I did not want to burden them with mine'. This demonstrates the complexities around community-based support groups. Nevertheless, Somali families need workshops and support groups to bring more awareness regarding NDD within the community.

The term 'family centred practice' is based on 'respect and acceptance for families' ethnicity, in line with the Equality Act (2010). This means that settings should be culturally responsive to individual families. For example, research conducted by Harry *et al.* (1999) looked at seven families from different ethnic backgrounds and their view on their child's disability when planning services for their child. The findings shows that these families' thoughts about their child's disability was based on their cultural backgrounds, which was different from the mainstream culture. This highlights that it is important for settings to understand what type of cultural context and beliefs they present to families who are unfamiliar with the culture of special educational needs. Thus, professionals should be open minded and take into consideration the cultural backgrounds of the families they work with to provide effective partnership when

working with Somali parents. However, if professionals working in partnership do not respect cultural backgrounds of families, this could be considered a barrier.

Early years settings can provide interpreters as a strategy when working in partnership with Somali parents. Parents in the Somali community expressed that language assistance and good communication within early years settings will help them overcome any language barriers they experience (Fox *et al.*, 2017). It is believed Somali parents often approach family members first if they have a concern about their child, rather than seeking professional advice (Bukket *at al.*, 2015; Fox *et al.*, 2017; Louong *et al.*, 2009). However, families often inform Somali parents not to be concerned (Fox *et al.*, 2017; Jagatheesan *et al.*, 2010). This highlights why it is important for settings to meet the needs of parents through providing language interpretation. Nevertheless, settings are hesitant to offer language interpretation due to the concerns about the interpretation quality (Lynch and Hanson, 2004; Ohtake *et al.*, 2000). On the other hand, research conducted by Schweitzer *et al.* (2021) highlights that parents with limited English skills benefit from the availability of competent and knowledgeable interpreters. Therefore, early years settings should be encouraged to identify and support Somali parents with limited English.

<u>Continuous professional development</u>

It is essential for practitioners to be culturally sensitive and aware of the religious and cultural practices Somali parents employ to enable a trusting and supportive environment (Ravindran and Myers, 2012). Research shows that parents from diverse cultural backgrounds with children with NDD reported that professionals regularly used language that was complex for parents to understand (DuBay *et al.* 2010; Hussein *et*

al., 2019, Louong *et al.,* 2019). This caused parents to experience anxiety, stress, and sadness during the early stages of their child's disability diagnosis (Moh and Mogiati, 2012). Therefore, it is important for settings to provide continuous professional development for practitioners working closely with children with NDD and Somali parents. The role of a practitioner is to enhance the pedagogical quality of service they provide for children and families (European Commission Thematic Group on ECEC Quality, 2013). Furthermore, continuous professional development enables practitioners to enhance their skills and identify areas for improvement in their daily practice (Peeters *et al.,* 2015). Research by Smith *et al*. (2023), based on Somali mothers' experience on parent-teacher relationships, found that mothers felt professionals lacked knowledge, skills, and experience regarding their child's NDD disability and felt that the provision was not supporting them enough. It is important that practitioners understand that Somali parents are most likely to face challenges within their community due to the stigma around NDD and may lack confidence (Abdullahi et al., 2017). This highlights that practitioners in early years settings must receive relevant professional development surrounding NDD within the Somali community.

Conclusion

This literature review has revealed the complex situations that Somali parents with children with NDD face. Through an extensive analysis of literature, the researcher has gained a comprehensive insight into how settings can support Somali parents with children with NDD. It is apparent from previous research and literature there are challenges and barriers Somali parents face in understanding their children with NDD.

Barriers such as language were explored, highlighting the difficulties Somali parents experience in understanding their child's NDD diagnosis and the support they need.

This literature review provided a better understanding surrounding the cultural stigma Somali parents experience in relation to their child's disability. The researcher highlighted the lack of awareness and beliefs regarding NDD and parents' feelings towards how the community perceive them (Fox *et al.*, 2017, p.308; Selman *et al.*, 2018). Strategies early years settings can implement to support Somali parents were highlighted with reference to parents' partnership, and continuous professional development. Ultimately, the barriers the Somali parents face due to cultural beliefs suggests why it is crucial early years settings implement strategies to support families within the Somali community. The next chapter will discuss the methodology used for this research study.

Methodology

Introduction

Methodology is referred to as the principles and values that guide research processes (Paul *et al.,* 2007, p.42). Methodology allows researchers to understand and address the research design, with reference to the paradigm and approach (Kumar, 2014, p.6). Within this chapter, the researcher will justify the research design, methods, ethical considerations, and explain the sampling strategy used for this study. The key question is: How does one nursery setting support Somali parents in early years with children with neurodevelopment disorders? To understand the participants' knowledge of the question and the exploratory nature of this study, three subsidiary questions were chosen, which follows:

1. What types of Neurodevelopment disorders are seen in the Somali community?

2. What barriers do settings face when supporting Somali parents with children with neurodevelopment disorders?

3. What strategies can settings provide to support Somali parents with children with neurodevelopment disorders?

Research design

Paradigm

This research used an interpretive paradigm that undertakes a qualitative research method. This method enabled the researcher to focus on the participants' own beliefs

and reasoning, and allowed in-depth, detailed data to be collected (Glesne and Peshkin, 1992, p.8; Myers, 2008). An interpretive paradigm is the process of looking at the world and interpreting social phenomena, such as culture, society, and language (Schwandt, 2001, p.134). The researcher used an interpretive paradigm as it focuses on individuals' beliefs and reasoning (Myers, 2008). Bilimoria (1998) explains that one's own experiences and backgrounds become a strength in an interpretative paradigm, which enabled the participants to connect with the researchers' own encounters and background experience within the Somali community, to strengthen the data collection.

Research approach

By using an interpretive paradigm, the researcher was able to apply a qualitative approach to collect data. A qualitative approach enabled the researcher to gather an in-depth, complex, and detailed understanding of meanings and behaviours that focused on context-specific phenomena in a naturalistic setting (Cohen *et al.*, 2017, p.289; Glesne and Peshkin, 1992, p.8). This was important for this study as it enabled more flexibility for the researcher to explore participants experiences and challenges, and obtain detailed data (Kumar, 2019, p.238; Mukherji and Albon, 2018, p.240). A study by Palinkas *et al.* (2015) explains that a qualitative approach is a small-scale study, compared to a quantitative approach. While a quantitative approach focuses on certainty and investigates by utilising statistics to analyse data, a qualitative approach focuses on acquiring an in-depth understanding of phenomena. Given the exploratory nature of this study, the researcher found a qualitative approach was important to understand the experience of Somali parents with children with Neurodevelopment disorders (Denscombe, 2017, p.6).

Case study

A case study approach was used to gain an understanding of participants within the Somali community. A case study is a practical method that investigates a contemporary phenomenon in order to understand real life cases in depth (Yin, 2017, pp.9-10). A case study approach allows researchers to focus on the details and relationships associated with procedures within a social setting. For example, the relationship between the setting and the Somali parents was explored, and the researcher had the opportunity to go into appropriate detail to unravel the complexities Somali parents face in receiving support for their child with Neurodevelopment disorders (Denscombe, 2017, p.77; Simon, 2009, p.4; Thomas, 2016, pp.3-5).

Methods

A research method is the building block of a systemic process of collecting, analysing, and interpreting data to gain a better understanding of the research topic (Patten and Newhart, 2018, p.3). A well-designed research method enables the researcher to collect data that is appropriate, reliable and avoids bias (De Vaus, 1999, p.9). Therefore, the researcher carefully planned the research design to collect relevant findings that are applicable to the target population.

Semi structured interviews

Semi-structured interviews were used as a method for this research study as they enabled data to be collected that is deeply grounded based on participants' experiences. Semi-structured interviews allowed the researcher to be flexible and offer participants to bring meaning to the topic study (Hugh, 2017, p.178). Gallettan (2013, p.47) explains semi-structured interviews consist of open-ended questions, which

enabled the researcher to create a space for participants to narrate their experiences. Furthermore, open-ended questions allowed the researcher to gain in-depth, valid, and reliable information to utilise the participants' responses and examine the data collected. This was an advantage as the participants provided responses that accurately reflected their personal perspectives (Edward and Holland, 2013, p.73).

Interviews were carried out in person, which posed an advantage for the researcher to document verbal and nonverbal signals that participants demonstrated (Creswell, 2013; Hugh, 2017, p.178). The semi-structured interviews were carried out with four participants and took place in a 'parent's meeting room', which was the participants' preferred choice. Davies and Dwyer (2007, pp.259-259) highlight that interviews must be held in an environment that is comfortable, free from distraction, and familiar to participants, to enable them to talk freely about sensitive and confidential matters. In line with BERA (2018), the interviews were recorded to guarantee accuracy of transcription and were stored in a password protected phone to ensure confidentiality and anonymity. The raw data will be destroyed on completion of the researchers' degree, as stated in the research proposal, ethics, and written consent forms.

A pilot study was carried out to devise the interview questions and understand prompts that could evoke deeper descriptions of participants' experiences. Baker (1994, pp.182-183) explains that a pilot study in research is used to test the sufficiency of a research method and assess the feasibility of the research questions. The researcher conducted a pilot study for the semi-structured interviews and focus group questions with some university students who are studying Early Childhood Education and Care, which allowed the researcher to gain an understanding of whether the questions were appropriate and relevant (Connelly, 2018, p.411). The interview questions were

modified and rephrased after feedback from the pilot interviews, due to students finding some of the questions difficult to understand, and the researcher was advised to avoid using jargons. This ensured the questions were easy to understand for participants who spoke English as a second language (Fox, 2006, p.5).

Focus group.

This research used a focus group with Somali parents to explore their perceptions of their children who have NDDs. Focus groups are commonly used in qualitative research to gain an in-depth understanding of a social issue (Nyumba et al., 2017, p.20). Beck *et al*. (1986, p.73) refer to a focus group as an informal discussion with selected individuals on a specific topic, which enables participants to focus on a topic selected by the researcher. In a focus group discussion, the researcher takes the role as the 'facilitator' or the 'moderator'. Within this study, the researcher facilitated a group discussion for Somali parents to express their experiences and the challenges they face within their community, which made the role of the researcher peripheral (Bloor *et al.,* 2001, pp.4-7; Johnson, 1996, Kitzingger, 1994). Linney *et al*. (2020) used focus groups as a method to collect data from the Somali community regarding mental health, which enabled a 'safe space' for participants to confidently express their opinions, in turn allowing the researcher to gather in-depth data (Silverman, 2016, p.351). For this study, the researcher wanted to create a 'safe space' for participants in the focus group as this was a sensitive and personal topic.

The focus group lasted for ninety minutes with five Somali parents with children diagnosed or suspected of NDD. The focus group arrangement did not discriminate against Somali mothers who did not speak English as translation was made available for them (Slaughter *et al*., 2007, p.6). The researcher provided a cover letter and

open-ended questions written in both English and Somali, to invite Somali parents to discuss their experiences within their community regarding their child's neurodevelopmental diagnosis. The setting distributed the cover letter and questions to recruit Somali parents for this study. The focus group questions focused on participants' perceptions of NDDs, their personal experiences with NDDs within the Somali community, how the setting provides support, and the difficulties Somali parents have experienced to seeking professional help. The group interviews were transcribed and translated by the researcher and audio recordings were stored in a password protected phone and will be destroyed on completion of the researchers' degree, as detailed in the research proposal, ethics, and written consent forms (Slaughter *et al.*, 2007, p.6). Temple and Young (2004, p.165) argue that translating data is challenging as 'meaning is constructed', especially if the research is related to a sensitive topic, which means that translating data is not straightforward. Nevertheless, the researcher was ethically compliant and ensured the transcripts were translated accurately to advocate the voices of the participants.

Triangulation

Triangulation is commonly referred to in research as a method that involves the use of two or more methods (Heale and Forbes, 2013). Bryman (2004) describes triangulation as the use of multiple approaches, such as theories and methods to investigate a single phenomenon. Furthermore, Williamson (2005) states that triangulation was originally introduced as a qualitative method to prevent potential bias occurring from the use of single methodology. This influenced the researcher to compare the findings from two different methods to identify patterns, which increased

the validity and reliability through verifications (Tashakkori, 2003). Therefore, triangulation was applied to this research study.

Sampling

This research study used a non-probability purposive sampling strategy to attain a concentrated variation sample. A non-probability purposive sampling technique is commonly used in qualitative research to target a particular group in small-scale research and allows the selection and identification of information-rich cases (Cohen, 2017, p.26; Parton, 1990, p.169). Morse (1991, p.129) states that purposeful sampling allows researchers to select participants with particular knowledge and experience to enable the phenomena of a research topic to be understood. Thus, the researcher used a non-probability purposive sampling strategy to select participants who had connections to the requirements for this study. This allowed the researcher to gain a deeper understanding of participants experience and perceptions as the research question specifically targets the Somali community.

The population of interest for this research study was Somali parents who have children with NDDs, and practitioners who work closely with Somali children and their parents at an early year setting located in Birmingham. In order to recruit a purposeful sample of participants for the focus group, the researcher worked closely with the gatekeeper of the setting and provided cover letters for Somali parents in English and Somali. The sampling size for this study was five parents who met the criteria, which required participants to be Somali parents with children with Neurodevelopmental disability, in order to achieve a concentrated variation sample (Cohen, 2017, p.267).

Additionally, the researcher recruited four participants who work closely with Somali parents for the semi-structured interviews, and the participants had a range of experience and qualifications, which allowed the researcher to gather in-depth data for this study (Etikan *et al.*, 2016, p.2).

Ethical considerations

Ethics is referred to as moral behaviours and values that guide the conduct of research (Wiles, 2010, p.128). Researchers are obligated to protect the rights and welfare of participants and gain ethical approval to ensure moral values and laws are followed (Denscombe, 2010, p.60). For this study, the researcher ensured the integrity of participants and the research data and obeyed the Newman University's ethical guidelines (Newman University, 2020) and adhered the British Educational Research Association ethical guidelines (BERA, 2018). Furthermore, the ethics form for this study was checked and granted by the Newman University ethics committee.

Anonymity and confidentiality

The BERA (2018, p.6) guidelines state that researchers must respect all participants autonomy and dignity, which means respecting individuals age, gender, sexuality, ethnicity, class, religion, disability, language and so on. As this research study involved participants from migrant groups, the researcher respected all participants' cultural and religion differences. To protect the participants anonymity, the researcher ensured the settings' location and participants' names remained anonymous, therefore, code names were used (Bell and Waters, 2018, pp.50-53). While the participants were assured of confidentiality, participants were informed that university tutors will have access to the data from the research study, and confidentiality may be breached in the event of a safeguarding concern. Although the researcher was not working directly

with children, in the case of a safeguarding concern, the researcher would have to follow the settings safeguarding procedures and policies. The researcher would be required to inform any concerns to the settings' Designated Safeguarding Lead (DSL) and their dissertation supervisor. Due to the sensitivity of the research topic and the fact that the interviews were recorded, participants were given the right to freely withdraw from the research project at any given time and were reminded that their data would be eliminated and destroyed from the research. The General Data Protection Regulation (GDPR, 2018) highlights any data collected must be kept confidential. Therefore, the researcher informed participants that the data collected from semi-structured interviews and the focus group were recorded and any documents containing their information will be stored in a password protected phone (MacNaughton, 2010, p.77).

Gaining consent

To gain access to the setting, the researcher provided sufficient information on the purpose of the study to the gatekeeper and gained written consent. Blaxter *et al.* (2010, p.161) explains that gatekeepers in research terms are referred to as the person who grants access to the participants and are usually in a position of management. In this case, the gatekeeper was the manager of the setting, and once consent was permitted from the gatekeeper, the researcher ensured all participants were provided with a cover letter detailing full information relating to the aim of the study, and participants were given written consent forms to complete and return to the gatekeeper if they were happy to take part in the study (Denscombe, 2014, p.109). Participants with English as a second language were given cover letters in Somali. Due

to the sensitive nature of the study, it was important participants had clear understanding of the research aim and objectives, therefore, translating the cover letter ensured any communication barriers were eliminated. This enabled a smooth process for Somali parents to take part in this study and there were no issues with the translation process (Fathi, 2013). In line with BERA (2018, p.18), participants were assured the right to withdraw from the study at any time without a reason and were informed any information they provided would be destroyed and excluded from the study.

Maximising the benefits and minimising risk or harm

In accordance with BERA (2018, p.14), researchers have a duty to maximise benefits and minimise risk or harm for participants, others, and society. Therefore, the researcher considered the potential risk or harm this study could cause on the Somali community, and believed the study will benefit the lives of the participants and the setting involved. The researcher hopes this study will be positive in bringing awareness to the challenges that Somali parents face when dealing with NDDs and subsequently improve the support settings could provide.

Conclusion

In conclusion, this chapter justified the research design that was used for this study and carefully carried out the data collection using semi-structured interviews and a focus group. The following chapter will present the findings and analysis surrounding how one setting supports Somali parents with children with NDDs.

Findings and Analysis

Introduction

This chapter will present data from the semi-structured interviews and the focus group and will analyse findings using literature from the literature review (Kumar, 2014, p.317). The intent for this research was designed to find out how one nursery setting supports Somali parents with children with NDD. For the purpose of addressing the research question, three subsidiary questions were devised, which was highlighted within this dissertation. The data from the semi-structured interviews and the focus group was analysed using thematic analysis. Braun and Clake (2021, pp.30-31) describe thematic analysis as a method for developing, analysing, and interpreting patterns of data in qualitative research, which involves systemic procedures of data coding to develop themes. The choice to apply thematic analysis for this study was influenced by the flexibility of the method as it provides data that generates rich, in-depth, and complex narratives of themes (Braun and Clarke, 2006). After a careful transcription of data, using display techniques such as tables and a colour coding system, the data was compared and interpreted in to two themes, which will structure this chapter.

To protect confidentiality and anonymity, the researcher will produce a code name for all participants involved in this study, to respect participants by not revealing their names (BERA, 2018). The practitioners in the semi-structured interviews will be referred to as practitioner 1-4 (see Table 1). The Somali parents within the focus group will be referred to as participant 1-5.

Table 1: Summary of practitioners' details

Code	Role within the setting	Qualification	Experience within the setting
Practitioner 1	Key worker	Level 3 in childcare	A few months
Practitioner 2	Key worker and speaks Somali	Level 3 in childcare	10 years
Practitioner 3	Manager and SENCO	Level 6 in Early Childhood Studies and Education	15 years
Practitioner 4	SENCO	Level 3 in childcare	5 years

Theme 1: The cultural perspectives of NDD

The first theme that was identified from the data analysis in the study was the cultural perspectives of NDD within the Somali community, which can be considered a barrier for early years settings when supporting Somali parents.

Lack of awareness

Due to the lack of awareness surrounding how NDD is perceived within the Somali community, participants from the focus group expressed that they had no knowledge

of NDD before their child's diagnosis. A lack of knowledge and acknowledgement of ADHD and ASD was highlighted by participant 1 and 5, who explained that the Somali community does not talk about NDD in social settings. This was a recurring theme amongst all participants who had not encountered NDD before their child's diagnosis. Reflecting on the literature review, Thomas and Rushford (2015, p.113) reported that certain disabilities within the Somali community are limited. The fact there is no word in the Somali language for ASD and ADHD could be linked to participants' lack of awareness of NDD (Fox *et al.*, 2017). However, further findings suggest that all participants believe people in the Somali community are very secretive and tend to hide disabilities. These views could be linked to the lack of visible symptoms and cultural perceptions surrounding NDD. Schuman and McDonald (2004) explain that traditional beliefs in the Somali community justify symptoms of NDD as a result of evil spirit possession. This could explain why Somali parents tend to hide their child's NDD diagnosis from the community.

Furthermore, it was recognised in the focus group that participants' understanding and acceptance of their child's NDD diagnosis was challenging, as most of the participants expressed, they did not recognise symptoms of ASD, including those who spoke fluent English. Participant 4 also reported that she did her own research to better understand her child's disability. However, participant 3 and 4 expressed they still found it challenging to comprehend symptoms of ASD. These findings suggest there is a lack of awareness surrounding NDD within the Somali community, which correlates with findings in research studies by Fox *et al.* (2017) and Barnevik-Olsson *et al.* (2008). However, it is difficult to say whether the participants generally lack awareness surrounding NDD or if it is due to cultural perceptions of NDD.

Language barrier

Language can be considered a barrier for Somali parents in understanding their child's NDD diagnosis. A study by Fox *et al.* (2017) highlights Somali parents expressed their frustration in understanding and comprehending their child's diagnosis process. Similar concerns were expressed by practitioners in the setting regarding language barriers, as they explained that they have many parents with limited English, and language in the Somali community regarding NDD is limited, even with translation. These results support the idea that limited English abilities can prevent Somali parents to fully engage in conversations with professionals during their child's assessment process (Miller-Gairy and Mofya, 2015). This could lead to Somali parents not understanding the settings' diagnosis process, which could delay support for children. However, issues relating to language barriers were not particularly prominent in the focus group, as most participants spoke fluent English. While most participants did not express language as a barrier, they expressed difficulties in understanding services and resources relating to NDD and found it challenging to find support in the health systems. Similar findings from Khanlou *et al.* (2017) and Smith *et al.* (2023) research studies reveal immigrant mothers found it difficult to understand information relating to their child's NDD diagnosis. These findings are similar to those of Fox *et al.* (2017), which highlights Somali parents felt discouraged in navigating the system. However, for this study, with the small size of sample, cautions must be applied as the findings might not precisely show the language barriers Somali parents face in the setting. Nevertheless, the findings in this study indicate the setting faces communication barriers when supporting Somali parents with children with NDD.

Cultural stigma

It is thought that traditional beliefs surrounding NDD could stop Somali parents seeking help, due to parents receiving little sympathy from their families (Tomlinson and Abdi, 2003). Concerns surrounding cultural stigma were mentioned by all participants in the focus group, who explained family and friends tend to disregard their concerns in relation to their child's NDD, and revealed there is a massive misunderstanding within the community regarding hidden disabilities. Participant 2 and 3 highlighted family members were in denial about their child's NDD and blame the parents for seeking help. These views reflect those of Gary (2002), who reports that the negative cultural perception of NDD leads to Somali fathers not accepting their child's diagnosis, which in turn makes Somali mothers feel lonely and isolated. Furthermore, this perception of NDD within the Somali community is addressed by Alakerrki (2022, p.3), who highlights that Somali parents refrain from community and social gatherings if they have a child with a disability. This could be due to the stigma and blame Somali parents face surrounding their child's NDD.

Most participants explained that extended family members downplay their concerns and discourage them to seek help as they believe their child would eventually grow out of it. However, this could lead to negative perceptions surrounding NDD and parents isolating themselves from their community, as Gary (2002) explained that Somali families rely heavily on extended families' opinions. This perspective was further expressed by participants, who explained they hid their child's diagnosis from the community due to fear of stigma and the lack of knowledge of NDD within the community. Participants claimed that their child's behaviour was disregarded as they were not considered 'normal' by the community. This opinion is similar to findings

discovered by Selman *et al.* (2018), which revealed Somali parents felt ashamed or guilty for their child's disability and led to some parents hiding or delaying their child's assessment process. This suggests that, due to stigma from extended families, Somali parents may find it challenging to accept support from settings for their child's NDD diagnosis, which can impact their child's development.

Practitioners within the semi-structured interviews found there were cultural barriers when supporting Somali parents with children with NDD. Practitioner 3 reported extended families have an influence on Somali parents' perspectives to receiving support for NDD. Furthermore, practitioner 4 explained it was challenging to bring up conversations with parents about their children because of fear of assessment. Selman *et al.* (2018) recognised that Somali parents deliberately isolate themselves to avoid discussing their child's behaviours. This signifies the cultural challenges Somali parents face that can impact accepting help from professionals. On the other hand, the participants in the study were optimistic and disclosed that religion has been the main source of strength in helping them come to terms with their child's diagnosis. Participant 1 and 4 believed their child's diagnosis was a test from Allah and they were special to be chosen by him. Similar findings were also seen in research by Fox *et al.* (2018), which revealed religion has a positive impact on Somali parents' perspectives of NDD and acceptance of their child's diagnosis. This suggests the participants in this study embrace religious beliefs and use it as source of comfort to accept their child's NDD.

Interestingly, the majority of participants argued that MMR vaccinations are the cause of their child's NDD diagnosis, and they believed NDD only happens in Western countries. Participants 3 and 4 believed vaccinations caused their child to develop

NDD. These views were also seen in research findings by Wolf *et al.* (2016) and Miller-Gairy and Mofya (2015), who highlight Somali parents believe NDD, such as ASD and ADHD are caused by environmental changes and vaccinations. However, participant 1 did not agree with this opinion and explained her son did not have the vaccination and was diagnosed with NDD. Nevertheless, limited research is available regarding the relationship between vaccinations and NDD, therefore, it is difficult to say if these views are true or not (Bettman *et al.*, 2015). Thus, findings from this research study suggest that culture is a massive barrier for Somali parents with children with NDD. Ultimately, the practitioners in the setting understand the barriers Somali parents face within their community and are patient and understanding when working in partnership with parents.

Theme 2: Strategies to supporting Somali parents.

Parent partnership

Parent partnership can have a positive impact on Somali parents with children with NDD in early years settings. Robson (2006) explains that a practitioners' role is paramount in successfully supporting children's development through parent partnership. Additionally, Stewart-Brown *et al.* (2004) claim that promoting parent partnership could improve parents' mental health during their child's early diagnosis process. In the focus group, all of the participants felt the settings' manager was helpful in supporting them to gain access to the best help for their children. Participant 1 explained that the manager of the setting was supportive and understanding of her needs. Furthermore, participant 4 and 5 highlighted the setting is a safe space for Somali parents to seek help and support. Harry *et al.* (1999) highlight that it is

important for settings to provide culturally specific support for parents as their cultural backgrounds may affect them receiving support. This indicates it is advantageous when the setting understands and accommodates to Somali parents' cultural beliefs when providing support. On the other hand, the fact that the staff are predominantly Somali at the setting could indicate why practitioners are understanding of Somali parents' cultural barriers.

In the semi-structured interviews, practitioners were asked if there is any specific support the setting provides for Somali parents with NDD. Practitioner 4 explained the setting provided a workshop for Somali parents about autism awareness, however not many parents attended. Practitioner 3 also highlighted that the setting liaises with the autism independence team in Bristol, to host culturally specific workshops for Somali parents. Rosenblatt's (2018) research findings highlight providing workshops that are culturally specific for Somali parents supports them to reduce stigma and increase NDD within the Somali community. However, in the focus group, participant 1 and 2 voiced that they wanted the setting to do more to bring awareness of NDD, by involving the wider community and not just parents with children with NDD. In addition, participant 1 expressed she would love to assist in debunking cultural stereotypes surrounding NDD within the Somali community. Hussein *et al*. (2019) believe it is important for settings to connect with community members to provide culturally specific services for Somali parents. Similarly, DuBay *et al.* (2018) highlight that parents with children with NDD who avoided sharing their children's diagnosis benefited from support groups with other parents who are experiencing similar problems. However, the findings in this research show that the setting is already involving the community to bring NDD awareness. This suggests the setting has a

good influence on Somali parents, as most of the parents in the focus group agreed the setting is meeting their needs. Nevertheless, bringing NDD awareness to the wider community would certainly reduce cultural stigma and isolation within the Somali community.

Continuous professional development

It is important for practitioners to be professional when working in partnership with Somali parents. Lilly (2019) highlights that parent partnership involves good communication, trust and respect between parents and practitioners. Participant 1 expressed her dissatisfaction with a Somali practitioners' professionalism in the setting and felt the practitioners' comment made her feel discriminated and stigmatised. Similar findings were seen in a study by Smith *et al.* (2023), who found that mothers felt stigmatised by professionals who lacked knowledge, skills, and experience regarding their child's NDD, and believed that the setting was not supporting them enough. Moh and Mogiati (2012) explain practitioners with culturally sensitive knowledge around the religious and cultural practices can reduce Somali parents' anxiety and stress during their child's early stages of diagnosis. This demonstrates why it is important for early years settings to provide training for practitioners to be culturally aware and understand NDD when supporting parents.

Although participants did not mention interpretation as a barrier, few practitioners expressed they have to carefully choose who they ask to interpret for them, due to some of the practitioner's lacking knowledge and sensitivity. Participant 3 admitted that there should be cultural awareness training for practitioners to increase their knowledge in professionalism when supporting Somali parents. These responses reflect the views of Peeters *et al.* (2015), who believe continuous professional

development enables practitioners to enhance their skills and identify areas for improvement in their daily practice. Although practitioners attend regular training, the findings suggest that it is necessary the setting provides training relating to professionalism and NDD for all staff.

Conclusion

This research discovered the perspectives and experience of Somali parents with children with NDD, and how one setting supports them. The findings revealed the cultural factors that influence how Somali parents understood, deal with, and accept NDD. It is evident that Somali parents face social and cultural stigma within their community, which may affect them seeking help from the setting. The findings also revealed the setting provides culturally specific strategies for Somali parents in an attempt to bring more awareness of NDD within the community. However, it is vital that professionals working closely with Somali parents work in partnership to help them gain a better understanding of the cultural disparities within the community. Thus, more research is needed in understanding and acknowledging the challenges Somali parents face, and for the setting to provide better strategies for Somali parents with children with NDD to effectively meet their needs.

Conclusion

This chapter will conclude this study, highlighting the key findings and reflect on the research methodology. It will demonstrate that the methods used were appropriate and relevant to collect purposeful and valid data.

Reflection on Methodology

An interpretive paradigm that undertakes a qualitative research method was appropriate for this study as it enabled the researcher to focus on the participants experiences, reasonings and allowed in-depth, detailed data to be collected (Glesne and Peshkin, 1992, p.8; Myers, 2008). Upon reflection, a qualitative research method was advantageous as it allowed the researcher to focus on real life experiences and understand the behaviours, attitudes and beliefs that contribute to the perception of NDD within the community (Mukherji and Albon, 2018, p.240). Semi-structured interviews were used as a method to collect data from practitioners working with Somali parents with children with NDD (Hugh, 2017, p.178). However, one of the practitioners in the semi-structured interviews responded with very vague answers and did not answer some of the questions, which could be due to her experience within the setting (see table 1). For next time, the researcher would be careful in selecting practitioners who have long experience working with Somali parents as it would enable a deeper analysis of data collection (Edward and Holland, 2013, p.73). During the process of conducting interviews, the researcher learnt to appreciate the effort it requires to conduct an interview and facilitate a focus group. Through piloting the interview questions, the researcher was able to gain a valuable insight to the interview process, which subsequently aided the researcher to regulate the pace of

the interview questions and adapt a conversational approach during the actual interview (Connelly, 2018, p.411).

To gain a deeper understanding of the perceptions of Somali parents with children with NDD, a focus group was utilised (Nyumba *et al.*, 2017, p.20). However, it is important to recognise the researcher is a member of the Somali community, and it could be said the participants for this study felt more at ease disclosing and sharing their experience with one of their own. On the other hand, due to the small-scale research design and the exploratory nature of this study, it is relevant to interpret the findings as a glimpse into the experiences and perceptions of NDD within the Somali community. Nevertheless, this study was conducted in a professional manner without any complications arising.

Key findings

It was evident throughout the data analysis and the literature review there are cultural challenges Somali parents with children with NDD face. The findings suggest there is a lack of awareness of NDD within the Somali community, which made it difficult for Somali parents to accept and understand their child's diagnosis process. However, it is difficult to say whether the lack of knowledge and understanding of NDD is linked to the cultural perception surrounding NDD or the lack of visible symptoms of NDD (Schuman and McDonald, 2004; Thomas and Rushford, 2015, p.113). Furthermore, the findings in this study correlate with previous findings from research that sociocultural challenges have impacted Somali parents' perceptions of NDD (Fox *et al.*, 2017; Selman *et al.*, 2018; Gary, 2002). Somali parents expressed they felt socially excluded and stigmatised by extended families and the community due to perception

of NDD. The fact Somali parents experience stigma and social exclusion resulted in them hiding and delaying their child's NDD diagnosis. This highlights the cultural challenging settings may face in supporting Somali parents with children with NDD.

Language barrier was identified by the practitioners in the setting as a massive barrier for supporting Somali parents. However, the findings from the focus group show language barriers were not the issue, but the lack of understanding of services was more prominent (Miller-Gairy and Mofya, 2015). Nevertheless, while most of the participants did not indicate language as a barrier, it is important to recognise the setting still face communication challenges when supporting Somali parents with children with NDD (Khanlou *et al.,* 2017). This demonstrates early years settings should implement support to reduce communication barriers for Somali parents with children with NDD.

Within the analysis, it was found that effective parent partnership can have a positive impact on Somali parents with children with NDD (Robson, 2006; Stewart-Brown *et al.*, 2004). The findings in this study suggest the setting have developed a good relationship with Somali parents and have attempted to bring awareness of NDD within the Somali community. However, it was recognised by the participants in the focus group that the setting should advocate for Somali parents and provide community-based interventions to increase public awareness of NDD in order to reduce the social stigma surrounding NDD (Hussein *et al.*, 2019; Rosenblatt, 2018). Moreover, it is important professionals consult with Somali parents and understand the cultural difficulties within the community in order to provide support for them. Nevertheless, it is vital to recognise this study's findings are consistent with similar research based

within the Somali communities' perceptions of NDD, both locally (Fox *et al.*, 2017; Hussein 2019) and internationally (Miller-Gairy and Mofya, 2015).

Recommendations for settings working with Somali parents with children with NDD.

- Professionals should consider understanding the sociocultural challenges Somali parents face in order to provide support and meet their needs.
- Settings should try to integrate the wider community to bring awareness of NDD and reduce stigma.

Recommendations for future research

- For future research, for early years settings to provide a culturally specific support for this underrepresented community, it would be beneficial to recruit a wide range of Somali parents who do not speak English as they may have a different perspective and understanding of NDD.

In conclusion, the findings within this study could be beneficial for settings working with Somali families and can provide an insight to why some Somali parents may delay or refuse their children to receiving diagnosis. Finally, the researcher believes this research study will be useful for future practitioners to gain knowledge and better understand this underrepresented community in order to provide the best possible support for them.

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