



Deconstructing existing frames of the 'normal': an insight into the Lifeworld of Autism using Qualitative Interviews and Interpretative Phenomenological Analysis.

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ABSTRACT

There has been a wealth of research in the field of autism, however, this tends to focus on medical discourses or on the societal construction of disability. Based on critical consideration of previous perspectives, this study aimed to explore how autism questions traditional assumptions of the 'normal'. Participants were recruited through a gatekeeper and consisted of three parents of individuals with autism and two individuals employed by Time Specialist Support, an autism befriending service. The lifeworld of autism was accessed through five semi-structured ethnographic interviews utilising photo-elicitation. The interviews were analysed using Interpretative Phenomenological Analysis and three main themes were extracted from the data. These were 'Enabling Spaces', 'An Extension of the Self' and 'A Subjective Shared World'. A posthumanist perspective was adopted during data analysis suggesting that those with autism can achieve things we consider to be 'normal', but a nonnormative approach is needed.

KEY WORDS:	AUTISM	CAREGIVERS	POSTHUMANISM	CRITICAL PSYCHOLOGY	PHENOMENOLOGY
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Introduction

A Brief History of Autism

Autism was originally understood as a behaviour associated with schizophrenia (Bleuler, 1919) until Kanner (1943) coined it as a childhood syndrome that involves obsession with routine and problems with communication. However, Goodley et al. (2016:771) describes how the 'monstrous' portrayal of disabled individuals can be traced back much further than this definition. Goodley et al. (2016) also claimed that this is a point of cultural curiosity that captures the dominant feelings during a particular time. Murray (2012:72) termed this a 'zeitgeist' condition. An example of this is in the extermination of the disabled under Nazi Germany in 1939-1945, when there were attitudes to rid society of people that did not fit the Aryan ideal (Evans, 2004). Such events are examples of 'othering'. Vandekinderen and Roets (2016) define this as a process where certain individuals are denied their humanity because they are considered ontologically deviant from ideas of the normal. Therefore, othering is a consequence of human beliefs.

Since the coining of the term, autism has been intertwined with race and class issues. Douglas (2013) describes how autism was a diagnosis afforded to the white middle class. Bettelheim (1967) described how these mothers were the cause of their child's autism through their cold parenting style and deemed them refrigerator mothers. He believed that harsh treatment by mothers initiated a withdrawal into the self, causing autistic rocking, he compared this to the treatment of prisoners in concentration camps who also exhibited rocking. As the understanding of autism has increased, the American Psychiatric Association (APA) (2013: 50) define it as a disorder that is characterised by:

Persistent deficits in social communication and social interaction across multiple contexts [and] restricted, repetitive patterns of behaviour, interests, or activities.

One traditional model for understanding autism is the medical model (Bury, 2001). This attempts to explain the causes and deficits associated with autism and aims to find a prevention or cure (Jaarsma and Welin, 2012). An example of this model, by Wakefield et al. (1998), suggests that the cause of autism is the mercury present in the MMR vaccination. Chelation therapy was developed as a cure and involved the

removal of mercury in individuals with autism (Brent, 2013). However, the medical model has been accused of aiming for a society where those with autism are not present and instilling othering (Waltz, 2008).

In response to this model, Oliver (1990) founded the social model which views disability not as an individual impairment but as the limitation of opportunities imposed from society (Burchardt, 2004). Curran and Runswick-Cole (2014) illustrate that when parents learn of their child's autism diagnosis there is an expectation for them to grieve. The social model suggests that society has constructed this concept of personal and familial tragedy, and as a result claims it is society that needs to change not the individual. However, whilst this model is useful in explaining the role of society in disabling individuals, this model fails to account for the lived experiences of impairment and denies the role of the body in autism (Oliver and Sapey, 2006; Shakespeare, 2006; Goodley, 2013).

The neurodiversity movement aims to address the failings of both these models. Singer (1999) argues that the brains of autistic individuals are different but should be regarded as a normal human difference. However, there have been controversies within this movement as it argues that high functioning autistics are part of normal variation, whereas low functioning are still classed as autistic and therefore, others these individuals further (Jarsma and Welin, 2012).

Whilst previous models have attempted to make significant contributions to how autism is viewed. Goodley (2013) claims that a critical psychological approach accounts for the previous issues within other approaches. Through the lens of the posthuman, autistic bodies can challenge the normative ideas of what it means to be human.

Posthumanism and Autism

Braidotti (2006, 2013) criticises that humanism is based on the understanding of 'man' as an able-bodied, clear minded, European subject. Posthumanism aims to create a new ontology for what it means to be human, including those groups that have previously been excluded (Saur and Sidorkin, 2018). Unlike humanism, this ontology must not be thought of as an internalised phenomenon, but instead in terms of the connections between one another (Goodley, 2014). Barad (2007) demonstrated this through her concept of intra-action. This claims that distinct agencies do not precede

interaction but instead emerge through intra-action. This creates inclusions and exclusions; therefore, othering is a malleable and movable concept created by humans. Barad (2014:168) also claims that 'absolute separations' between individuals can never be produced and suggests everything is a connected agency that produces a collective knowledge.

One study that puts Barad's (2007; 2014) concepts to use is Frigerio et al. (2018). They looked at a case study of a mother and an autistic child and found the mother had separated herself from her daughter. She saw her through a medical view of traditional development and emphasised how she is different from other children her age. Through this gaze, she aimed to separate herself from her daughter's diagnosis. However, according to Barad, there are no absolute separate entities and so the mother and daughter's world must be thought of as connected and an outcome of intra-active systems.

Critical Autism studies

Traditional disability studies have been accused of working to exclude individuals with disabilities (Goodley, 2013). As a result, disability studies have taken a posthuman turn (Abrams, 2017). Goodley and Runswick-Cole (2016) describe how critical autism studies can be accessed through the DisHuman. This simultaneously asserts disabled people's humanity and the normative understanding of personhood, while also acknowledging the possibilities offered by disability to reshape and refashion traditional concepts of the human. MacLeod Budge and Wels (2016:141) worked alongside individuals with learning disabilities, and focused on the use of 'probeerruimte', which translates to creating space to try things out. This concept includes multiple meanings of space, both physical and psychological and has been linked to personal development and growth. They suggested that providing a space that was conducive to risk taking allows spaces where people who are rendered vulnerable are able to demonstrate risk and influence over their lives. Through the lens of the DisHuman, individuals were provided the same rights as other citizens and their humanity was asserted. It also reshaped what can be considered 'normal' as the disabled individual is doing things previously only assigned to the able bodied.

However, Vehmas and Watson (2014) criticised those writing from a critical stance and said that they are in danger of committing normative disorientation. They criticise

able-ism so much that ignore the fact that normative desires can lead to health, well-being and a good life. Goodley and Runswick-Cole (2016) responded by claiming that critical disability studies do not ignore these normative views, but instead look at ways that these normative desires can be achieved in a non-normative way. Goodley and Runswick-Cole (2015) demonstrated this when looking at a case study of the Derbyshire's. They had an autistic daughter and actively questioned how boundaries and borders can reaffirm disabled children's lives. Through her part-time retail job, she refused the fixed boundaries that meant disabled people could not work. This study highlights that challenging boundaries results in a normative achievement, however doing so questions the normative boundaries that govern this.

Caregivers occupying the lifeworld of Autism

Parents of disabled children are considered; allies, teachers, facilitators and advocates (Ryan and Runswick-Cole, 2008). Parents find themselves in the habitus of disability and occupy different lifeworlds to parents of non-disabled children (Mackenzie and Leach Scully, 2007). Cavlak et al., (2009) found that mother's quality of life and emotional stress were found to be more effected compared to fathers. Mothers are often depicted in a liminal position where they are either grief stricken or fighting for their child's rights in areas such as education, placing them in denial (Ryan and Runswick-Cole, 2008; Mallet and Runswick-Cole, 2014). Posthumanism criticises studies such as being androcentric and therefore, mothers will be viewed less favourably than fathers (Braidotti, 2013). Critical studies have attempted to investigate reasons behind mothers appearing unfavourably. They have found that mothers report many of the sources of burden and stress due to the encounters with strangers, practitioners and professionals (Runswick-Cole, 2007; Hodge and Runswick-Cole, 2008).

Normative models of the family claim families with disabled children fail to match up to norms (Lazarus and Folkman, 1984). However, there has been a turn to a 'corrective' approach in which the positive aspects of raising a child, are focused on (Goodley et al. 2014). The DisFamily is the simultaneous celebration of disability and its productive potential but acknowledges the normative ways of living in families when there is an individual with a disability (Ryan and Runswick-Cole, 2008). Burrow et al. (2008) found that the use of service dogs in families with autistic children meant the

dogs acted as a second caregiver and the relationship with the dog helped the parent feel safer. The dog would perform tasks such as stopping the child from running into the road. This represents the DisFamily as it shows that with the use of the service dog the family can be productive in a normative way whilst also celebrating the productive potential of autism. The use of a service dog as a secondary carer wouldn't be possible without the presence of Autism.

Due to the diversity of professionals operating within the lifeworld of autism, it would be difficult to study them all. However, Beals (2003) claimed that those who spend most of their time working directly with individuals diagnosed with autism are the closest researchers have to 'experts'. Agencies that provide support to families of those with autism aim to give breaks to parents and could be considered a secondary caregiver at certain stages in the child's life. Beals (2003) also calls for studies that report positive aspects of professional encounters as opposed to the negative side often reported (Osbourne and Reed, 2008). Within this study, parents and those providing support will be considered caregivers, and the positive aspects of occupying this lifeworld will be focused on.

Research Aims

- To understand how parents and support workers create a 'normal' life for those with autism.
- To incorporate a posthuman perspective, allowing an exploration of traditional ideas about how a 'normal' life is achieved.

Research Objectives

To understand how caregivers create a 'normal' life and to incorporate a posthuman perspective, ethnographic semi-structured interviews using photo-elicitation will be used. This data will be analysed using interpretative phenomenological analysis.

Research Question

How do those within the lifeworld of autism construct a 'normal' life for autistic individuals?

Methods

Qualitative research was deemed most appropriate for this study as it focuses on enriching understanding (Elliot et al. 1999) through exploring subjective experiences of individuals (Willig, 2013). The researcher took a critical realist approach, focusing on discovery but also recognising the subjectivity in knowledge production (Willig and Stainton-Rogers, 2008). This research utilised several imaginative research methods (Robson, 2002; Creswell, 2007). All these methods are interrelated; however, it is important to discuss them separately as they have their own defining characteristics.

Semi-structured interviewing

According to Banister (2011) the main feature of semi-structured interviewing is that they are shaped by a set of predetermined questions, allowing the interviewer to direct the conversation. Two interview schedules were developed in the study based on the differential experiences of the two groups (Appendix 1 and 2). These schedules are based on previous literature but allow for a degree of flexibility whereby the researcher can ask questions based on what the participant is saying (Edwards et al., 2018). Therefore, the questions allow the expert knowledge of the interviewees to be probed. This has been used extensively with parents of children with autism (Tait et al. 2016; Ballan 2012; Hampton et al., 2017; Heys et al., 2017; Chao et al., 2018; Hodgson et al. 2018). However, Atkinson and Silverman (1997) criticise these as being overused, especially with parents of children with learning disabilities (Runswick-Cole, 2011). To combat this, a combination of methods was used.

Ethnographic interviewing

Ethnography was developed in the 20th century where it was a means of investigating other cultures (Lambert et al., 2011). Malinowski (1922:25) claimed the goal is “to grasp the native’s point of view”. A characteristic of ethnography includes a concern for physical emplacement of the fieldwork in participants lifeworld’s, (Lambert et al., 2011) thus interviews were conducted in places participants were habitually frequent (Pink, 2015; Stevenson, 2014). Spradley (1979) claimed that, unlike traditional psychology where people are the subject of study, ethnography is about learning from them. Ethnographers take an ‘apprenticeship’ role and do not assume superiority of knowledge as participants are considered the experts (Lambert et al., 2011). Therefore, the researcher ensured that questions were not leading and were open-ended, allowing the participant to educate the researcher on their lifeworld.

Photo-Elicitation

Interviews alone do not always guarantee production of rich data (Schultze and Avital, 2011). As a result, photo-elicitation was developed to use photographs as prompts to facilitate rich responses (Collier, 1957). It does this by generating discussion and thus provides insight into lives (Dickie and McDonald, 2011; White et al., 2010). Pauwels (2013) claims that is because it triggers a deeper, more abstract perception of the participants' world. The images can be part of existing collections or purposely made for the researcher (Stevenson et al. 2019). In this study, participants were asked to bring photos they already had that described their lifeworld with autism and these were used as prompts in the interview (Collier, 1967). The researcher assumed an apprenticeship role which allowed the subject to be understood in a way that is subjective to them (Verstraete, 2009). This was commentary to the features of ethnographic interviewing.

Semi-structured ethnographic interviewing using photo-elicitation

An invitation letter was to the gatekeeper (Appendix 3) who then contacted potential participants. Once recruited, interviews were organised to be carried out in a place of the participants choosing. Three asked for the interview to take place at their home and two in a room at Time Specialist Support (TSS). As they were in their natural environment and felt comfortable, it prompted more in depth and meaningful conversation (Serrant-Green, 2007). At the beginning of the interview, participants were given a participation sheet (Appendix 4) and then asked to sign a consent form if they agreed to take part in the study (Appendix 5). Participants took part in a one-off interview lasting from 30 minutes to an hour. These were recorded on a mobile phone and were transcribed later (Appendix 6) and were stored on a memory stick. Participants were given the opportunity to bring photos along to the study that represented the world of autism/family life, two participants chose to do this. Upon completion of the study participants were thanked for their involvement and were given a debrief form (Appendix 7).

Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) aims to uncover how individuals experience a phenomenon and thus discover what this experience holds for them (Smith et al. 2009). Husserl (1970) argued that phenomenology should examine

experiences in the way they occur. The researcher should step outside of their everyday experience and disengage from the activity and reflect on the taken-for-granted assumptions surrounding it (Smith et al., 2009). However, later phenomenologists such as Heidegger (1985) claimed that a person is unavoidably a 'person-in-context' and experiences will always be embedded in some form of context (English, 2014; Smith et al. 2009). This approach was adopted in the study and the researcher entered a 'double hermeneutic' whereby they were involved in the interpretation of the interviewee's sense making, allowing the researcher to 'give voice' to the lived world of participants (Larkin et al., 2006). There was a need to be reflexive as the researcher was involved in this sense making, the researcher was mindful of the presuppositions brought to the study (English, 2014).

Due to the emphasis on the lived experience, interpretative freedom is afforded to the researcher, providing an opportunity to develop a theoretical framework that transcends the conceptualizations of participants (Larkin et al., 2006). This is useful when applied to those where a stressful phenomenon is a central part of their life, such as parenting a child with autism. This provides insight for those who don't often share their experience (English, 2014).

Phases outlined by Smith et al (2009) were followed during the analysis. Beginning with rereading the data case-by-case basis several times. This allowed the researcher to be fully immersed in the transcripts ensuring the participant was the focus of analysis. Initial themes were noted, and the analysis examined the semantic content and language use on an exploratory level which led to the development of emergent themes. As IPA is true of the ideographic approach, individual transcripts were analysed first before integrating meaning across the sample (Langridge and Hagger-Johnson, 2009). Following this, patterns across the five participants were identified and overarching themes were formed, example quotes were used to ensure they remained closely grounded in the data (Munroe et al. 2016) (Appendix 8).

Power in academic research

There is often an issue of a power inequality between the interviewer and interviewee (Yardley, 2000; Plesner, 2011). Hodge and Runswick-Cole (2008) showed there is often a mistrust between professionals and parents of children with autism, in this study it is possible that the parent may view the interviewer as a professional. The

methods used in this study aimed to overcome this. Photo elicitation was used because power relations are balanced out as participants take on the role of the expert (Auken et al., 2010; Pauwels, 2013). The ethnographic nature of the interviews meant a further reduction in power inequalities (Kvale, 2006) as participants chose the interview space, were comfortable in the environment and had a sense of control.

Furthermore, the analysis adds to feature of balancing out power inequalities. Howard et al. (2019) asserts that IPA views participants as the experts of their own worlds and argues that there is an equality of voice between the interviewer and interviewee. She also claims that through this equalising of power between autistic informants and non-autistic researchers the double empathy problem is addressed, which often discredits autism research. Milton (2012) describes this as when people with different experiences of the world interact and struggle to empathise with each other.

The researcher

Traditionally, ethnography involved studies of the unfamiliar aspects of the world. Consequently, it has often involved the researcher being an outsider gaining entry (Berry, 2011). More recently it has turned to looking at familiar aspects of the researcher's world (Serrant-Green, 2007). Yardley (2000) suggested that understanding the socio-cultural context of the group is important. While the researcher does not have the same experiences as the participants, they have gained an understanding of the world of autism through working as a support worker for TSS. Therefore, there is some multisensory, overlapping experiences between the researcher and participant (Pink, 2015; Moles, 2008). In research, this is encouraged as it increases the chance of discovering something serendipitous because participants feel more able to express their opinions (Rivoal and Salazar, 2013).

Participants

All participants were recruited through an association with TSS, an autism befriending service based in Manchester. Smith et al. (2009) recommend using three to six participants for an undergraduate or masters study using IPA. Five participants were recruited through a gatekeeper who worked at TSS (see table 1).

Name	Gender	Involvement with TSS

Molly	Female	Has two boys both diagnosed with autism and one using TSS.
Liz	Female	Has twin boys both using the service and diagnosed with autism.
Amy	Female	Works as a manager for TSS
Tia	Female	Founder TSS and works there
Jenny	Female	Has one child with autism that uses the service.

Table 1. Table showing characteristics of participants.

Ethics

Ethical issues were initially covered in the Ethos form (Appendix 9) and insurance checklist (Appendix 10). The issue of anonymity was addressed using pseudonyms and all documents were password protected. Whilst confidentiality could not be fully ensured due to the possibility of publication, participants were non-identifiable therefore, this was not an issue. Prior to the interview participants were given a participant information sheet, outlining the aims and purpose of the research. They were asked to agree to the terms of research using a consent form, meaning the issue of informed consent was addressed. Following the interview participants were fully debriefed and asked to sign a debrief form. Participants were not subjected to anymore psychological harm than they would be in their daily lives.

Analysis and Discussion

Upon analysis of the five transcripts, three main themes were deducted. These were 'Enabling Spaces' with a subtheme of 'A Normal Family', 'An Extension of the Self' and 'A Subjective Shared World'.

Enabling Spaces

Cresswell (2015) asserts that a space becomes a place when meaning is attached to it. These places are essential for the expression of belonging and the development of identity (Cameron, 2005). Hall (2010) claims that place is essential for people with learning difficulties, claiming they are more likely to be excluded from mainstream space, which provide these functions for 'normal' individuals. It is important to consider place as not just a geographical location but a fluid idea that is moveable and contains intersubjectivities. This theme will look at the places that those with autism can be and become (Goodley and Runswick-Cole, 2015) and explore how intersubjectivities play a role.

“[...] we have Adam who does some work experience here who has autism [...] he always wants to speak to an angry parent [...] Sometimes when I'm not in the office I'll phone up and be an angry parent when he answers [...]” Tia (21-31)

This quote shows that the space of TSS is used to help an individual with autism complete work experience. He feels comfortable expressing that he wants to speak to an angry parent. In a space that was designed to be used as an office for the daily running of TSS, this space now provides Adam with work experience that is often difficult for those with autism to acquire (Wagner et al., 2003). This transformation from space to place and is an example of Thirdspace (Soja, 1996). Joanou (2014) suggests that Thirdspace provides a framework in which groups excluded from certain spaces can succeed despite adversity. The space at TSS allows Adam to succeed at work experience despite being excluded from many work spaces due to his autism. Like the experience of the Derbyshire's (Goodley and Runswick-Cole, 2015) whose daughter who was able to work in a retail shop, Adam can be himself at TSS, showing he is comfortable within this space. It also highlights the importance of enabling relationships, Adam feels confident around Tia, suggesting that it is not just the physical space but the people that are involved.

However, for a space to be enabling, there needs to be an element of risk taken by those involved in the construction of the space. This is to encourage 'probeerruimte' (MacLeod Budge and Wels, 2016:13) so there is a chance for them to try new things out.

“[...] they were just like let’s all sit around and sing old MacDonald. There was nothing to push them out in to the community [...]” (Molly, 6-7)

This quote shows that when Molly looked for previous support for her child they provided childlike activities. This suggests that those who are involved in the construction of this space are not using an element of ‘probeerruimte’. Saltes (2017) claims that ableism allows the construction of spaces that exclude and keep them “in their place” (Kitchin 1998:343). This is an example of this, as the interests that were expected of autistic individuals were reduced to those interests that represent a child and would not be acceptable for others their age, reinforcing a less-than-human status. Saltes (2017) claims that disabled individuals are constantly navigating these spaces. She claims that rather than do this passively, these spaces are actively challenged and reconfigured. Molly is actively challenging these spaces on her son’s behalf. Showing the importance of intersubjectivities in enabling spaces.

However, TSS provides a space where they can perform age appropriate tasks.

“[...] it was used as a befriending service [...] he was getting to that age where he didn’t want to be seen with his parents anymore [...] to help build his confidence [...]” (Molly, 18-21)

Molly describes her use for TSS as a befriending service that increases confidence, that would be present in typically developing children. Those working for TSS provide support in the same way Burrow et al.’s (2008) showed autistic guide dogs being used as a secondary caregiver and allowed the performance of ‘normal’ activities. TSS does not operate in one physical space, showing how spaces do not need to be geographical in order to allow autistic individuals to be and become (Goodley and Runswick-Cole, 2015). This is an example of the DisHuman as personhood is asserted by providing a space that allows them to perform age appropriate tasks, but also reshaping what it means to be human, as people often assume that autistic individuals cannot perform age appropriate tasks.

Sub theme: A Normal Family

This sub-theme looks at the ideas that spaces not only need to be enabling for autistic individuals, but also for the families to complete ‘normal’ activities. For families it is about recognising the needs of their child and adapting these spaces. The concept of

the DisFamily is illustrated here as it challenges the ideas that were previously thought of as belonging to disabled families, whilst also highlighting normative ways of being and living in these families.

“[...] We have a static caravan [...] it is a home from home, so he’s got his own room and knows where everything is [...] we have a dingy [...] he loves to lounge in that [...] you have to have an activity for him to participate in [...]” (Jenny, 54-57)

Jenny describes the caravan used for family holidays and how they have adapted this space to meet the child’s needs. Previous research has been concerned with how children with autism are likely to disrupt family activities (DeGrace, 2004; Roger and Umaibalan, 2011) and this often results in non participating in these activities. However, the research fails to account for how families are active shapers in their lives. For example, normative families are not limited in their holiday destinations. However, for Jenny’s family to take part in these family activities, they must take into account their son’s needs. This is an example of the DisFamily, as the normative ways of being in these families is asserted while also challenging the ways in which this can be achieved.

Spaces also provide an opportunity for intersubjective relationships to be worked on.

“[...] This is a picture of Cian with a red power ranger at comic con [...] his brother loves [...] it really allowed them to bond [...]” (Molly, 83-85)¹

Molly highlights how being in the space and environment of comic con has allowed her two sons to take part in bonding, this is often a struggle for those families with autistic members (Braconnier et al., 2018). However, spaces that hold a shared interest can facilitate this and through the utilisation of spaces such as these, sibling bonds and family connections are just as possible as in typical families. This is also an example of how spaces become places. The space that comic con occupies becomes representative of challenging the fixed borders that often say siblings with autism cannot bond. In the same way the Derbyshire’s daughter was able to bond with peers at a social club in which she felt relaxed (Goodley and Runswick-Cole, 2015), Molly’s sons are able to take part on social activities and overcome deficits described

¹ Photograph was unable to be included for ethical reasons.

by APA (2013). This questions whether the cures for deficits in social communication described by the medical model are needed, as social communication can occur in enabling environments.

An Extension of the self

This theme is encapsulated by Haraway's (1990:220) question "Why should our bodies end at the skin?" In Clark's (2008) theory of the extended mind, he presents the idea of active externalism, here objects within the environment function as part of the mind. He argues that there is an over separation between the environment, the body and the mind. This theme explores the idea that objects and people within the environment become an extension of the self, challenge the humanist idea of the self and therefore explores what it means to be human (Shildrick, 2014).

"[...] a grow clock [...] I set it at night and every hour a star goes out and when the time is up the sun comes up [...] so it helps him know when it's night or time to get up [...]" (Jenny, 109-111)

Jenny describes the grow clock as an object that helps her son tell the time and understand when he can get out of bed. The clock uses symbols that have meaning to the individual, such as knowing a star means night, harnessing previous knowledge and skills. In line with Clark's theory, Jenny's son's mind is extended into environment and thus the grow clock aids the function of his mind, in telling the time. Perel et al. (2008) describe how a prosthetic arm allows for self-feeding, as a normal arm would. Just as the prosthetic overcoming the absence of the arm, the grow clock aims to overcome the child's lack of awareness of time. From a posthuman perspective, the clock is helping her son overcome his difficulty in telling the time, allowing him to match up to norms through a process that is nonnormative.

These extensions of the self not only allow the individual to overcome the difficulties present in autism, but also allows an expression of the self.

"[...] the other day I recorded on these buttons "Billy stay" and "Billy go away" [...] he's such a monkey and he started pressing "Billy go away" and laughing [...]" (Liz, 230-234)

The recording device itself provides an opportunity for her son to have a voice and overcome the communication element of autism described by Wing and Gould (1979).

The device allows him to engage with objects in his environment to match 'norms' and also allows an expression of his personality, which he would not be able to achieve through verbal means and shows his 'monkey' side. Also, Saltes (2017) describes how disabled individuals are using technology to assert their presence in spaces they would have been previously excluded from. Due to his autism he would've been previously excluded from these verbal conversations with his brother.

However, whilst these extensions attempt to aid autistic individuals in becoming equal to others, there are issues with power when using these extensions. One example of this came from Amy and the use of PECS (Picture Exchange Communication System) (Bondy and Frost, 2001).

“[...] I will teach a child to use a PECS book [...] as soon as I've left it gets taken away [...] that PECS book is that child's voice [...] I wouldn't gag you [...] they're gagging that child [...]” (Amy, 156-161)

By removing the PECS from the child's environment, the teacher is reinforcing a less-than-human status, as you wouldn't gag a 'normal' human. The child is 'gagged' as they can no longer communicate their needs. Many autistic authors, such as Singer (1999), have reported the inequalities they have faced due to their condition. These authors can effectively communicate this inequality. However, some individuals lack these skills and by removing their only communication aid, it prevents individuals with autism speaking out about these inequalities and thus they are silenced.

In previous examples, extensions of the self have been understood in terms of technological or physical devices to aid the individual. However, through analysis, it became clear that intersubjectivities play a role in becoming an extension.

“[...] I do things like hold his elbow while he brushes his teeth cos' he finds it easier, but it still helps with the motor skills [...]” (Liz, 215-217)

This quote shows how Liz aids her son in brushing his teeth by holding up his elbow which helps him do this independently but aids him slightly with motor skills that he struggles with. By Liz holding up her sons elbow to aid him in brushing his teeth she shows how the mother-son relationship could be considered an extension of the self. This type of extension requires someone who understands the embodied experience of the individual with autism. In this case an understanding that sometimes, for her

son, motor skills can be an issue. These extensions are most effective when they mean the individual is playing an active part, for example, he is doing the brushing of his teeth himself. This builds on Clark's theory that did not account for intersubjective extensions of the mind. 'Probeerruimte' (MacLeod and Budge, 2016:141) can be applied here as there is space to try things out with a small amount of help. Without the assistance on the elbow it would not be possible to try out brushing his teeth on his own.

A Subjective Shared World

This theme challenges the assumption that those within the lifeworld of autism have the same perception of it. As previously seen, those basing their knowledge on perspectives such as; the medical, social, neurodiverse or posthuman, have different understandings and thus influence the lifeworld of autism in different ways.

“[...] parents are on different levels of their journey [...] some are struggling to come to terms with it [...] looking for that cure [...]” (Tia, 264-268)

This quote by Tia shows how, through her experience, some parents she has encountered have been at different stages of their journey and had different views about autism. Frigerio et al. (2018) demonstrated that when a parent viewed their child in terms of the medical diagnosis, this separated herself from a shared lifeworld and a process of othering occurred. Suggesting that having a medicalised view of autism is likely to be detrimental as it results in an attempt to escape the joint lifeworld they unavoidable share and results in othering.

Parents further along on their journey have a more posthuman view of autism.

“[...] He asks me to get him a glass of water [...] I say you've got autism you're not a paraplegic [...]” (Molly, 141-143)

This quote shows how Molly refuses to complete tasks for her son that she knows he is capable of. Showing that to occupy this shared world and enable the individual, there needs to be an understanding of the embodied experience. To get it the glass of water for him would disable him more, reinforcing the idea that he is less than human as you would not do this for a 'normal' human. Goodley and Runswick-Cole (2015) show that often those with physical disabilities are treated more preferably to those with learning disabilities. Molly refuses these borders that suggest that those with

autism are less able than those with, in this example, no limbs. She highlights how it is important to recognise what the autistic body is capable of and not simply generalise all disabled individuals.

However, there can sometimes be a lack of understanding about the experiences of the autistic body.

“[...] we had one young man who was very very sensory and did a lot of spitting [...] social workers took this as he was unhappy and being neglected [...] we were like no that’s just his thing [...]” (Tia, 180-182)

Tia’s experience with social workers has shown that many of them misinterpret the child’s behaviour as a symptom of neglect. Social workers are likely to approach this situation from the background of child removal and child welfare issues. This is an example of the social model (Oliver, 1990), as the social worker views the child without consideration of their autism, and views them as they would a ‘normal’ child. This shows the value of a posthuman perspective as Braidotti (2013) emphasises the importance of recognising people as equals, however considering the embodied experiences of the autistic body (Goodley, 2013).

Summary

When addressing the research question, this study showed the differential ways in which parents and caregivers positively influence the lives of those with autism, creating a ‘normal’ life. This is achieved through providing spaces that enable an expression of the self and spaces that allow the family to complete ‘normal’ activities. It is also clear that the understanding and perception of autism is a key influence in the lifeworld that all the participants occupy with autism. This understanding permeates and influences the spaces that the participants create. Extensions of the self provide a way to match up to norms and express personality, however, it could be argued that these extensions do more than this by questioning the fundamental meaning of what it is to be human. This study adds to the existing literature as it did not view parents and other caregivers as separate entities and acknowledges other influences on the lifeworld of the individual.

One limitation of this study could potentially be the methodology as it assumes that the caregivers have an accurate understanding of the lifeworld. It may be more

accurate to use individuals with autism in this study. However, due to one of the features of autism being problems with communication it may be difficult or misleading to conduct a study that relies solely on the spoken word. Therefore, a fully ethnographic study that involved the researcher being directly immersed in this lifeworld, through observations, would provide a more accurate understanding of the lifeworld of the individual. Although this study does not directly interact with individuals with autism, it acknowledges that the caregivers understanding, may not be representative, highlighting this limitation within the study. Therefore, this study does contribute to the understanding of how those with autism can engage in normative achievement.

Reflexivity

Reflexivity aims to enhance the accuracy of qualitative research (Berger, 2015). It does this by monitoring the credibility of the findings by considering the researchers values, beliefs, knowledge, and biases (Cutcliffe, 2003). My research was shaped by these through my involvement with Time Specialist Support and job as a support worker. I have had first-hand experience of the lifeworld of autism. When I first began looking at the research, I was disappointed that much of the research painted those with autism and parents in a negative light. Therefore, I adopted a critical psychology stance and thus filtered the research I included in accordance with this. Kacen and Chaitin (2006) claim that the researcher's worldview and background may affect the way they use language and pose questions, shaping the findings and conclusions of the study. However, whilst this may have affected my conclusions, Heidegger (1985) claims we are all unavoidably a person-in-context, therefore, all researchers are in some way influencing their results. My position proved useful when it came to the interview process as respondents are often more willing to engage in meaningful conversation when researchers are perceived as sympathetic to their situation (Bannister, 2011).

Before the interviews, I had looked at the research of Runswick-Cole and Ryan and assumed that all parents would be of the same opinion. Despite these researchers having children with autism themselves, I found that all of the caregivers in my study were of differing opinions including those in line with the medical model. I found this surprising and it suggests that views of researchers are not always in line with the

demographic they are researching. However, as Pillow (2003) claimed, researchers should position themselves as compassionate towards the research subjects and not imposing their ideas. Despite being of a different view to the participants, the epistemological design of this study allowed the lived experience of the participant to be revealed. In order to add to the understanding of the lived experiences, I provided them with an opportunity to bring photos along to the interview and engage in photo elicitation. Two participants chose to do this. Kagan (2012) said that in order to treat the participant as an equal they should have control over the research methods used. Allowing for creative and unexpected responses (Stevenson, 2015).

In terms of the implications for caregivers in the lifeworld of autism, this helped to reduce some of the stigma surrounding caregivers, which is often the subject of many research papers. It also highlighted the differing ways in which a 'normal' life can be possible for those findings themselves within this lifeworld. Through doing this, it has attempted to break down the barriers that often surround those with autism and highlight ways in which people can still complete normative activities. Considering myself to be somewhat part of the lifeworld of autism, I found it extremely enlightening to learn of some of the ways in which you can empower those with autism to achieve things you did not think was possible.

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