Title: 'I don't live with autism; I live with my sister'. Sisters' accounts on growing up with their preverbal autistic siblings.

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Abstract:

The experiences of siblings in early adolescent years who grow up with an autistic brother or sister have received very little research interest, especially in terms of sisters' experiences. Hence our understanding of wellbeing opportunities and challenges in siblings' everyday life is inadequate and not reflected in the current clinical practices.

Semi-structured interviews utilising an active, non-judgemental and curious stance to explore how sisters make sense of their everyday experiences (inspired by the notion of mentalizing) were conducted to capture important experiences of nine typically developing female siblings. Interpretative Phenomenological Analysis (IPA) was employed. The master themes included: (i) sisters' interactions with their siblings- 'I don't live with autism, I live with my sister' (ii) sisters' interactions with their parents- 'Always there for us, but often asking too much', (iii) practical struggles of caring- 'Like a lonely fighter, tired but always on duty', (iv) perceived sisters' needs- 'I care about my brother and I want society to care about us'. As experts of their own lived experience, sisters shed light on their day-to-day experiences. The themes derived from their experiences may help to draw attention to an appreciation of everyday life including planning for the parts that remain a struggle. This latter point is discussed in terms of implications and adoption of an existential view of wellbeing for future research and practice.

Keywords: Autism, Sibling Experiences, Interpretative Phenomenological Analysis, Family Mental Health, Wellbeing

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Introduction

Sibling relationships play a central role in family life and are the first most intense peer relationship that the child experiences (Powell & Gallagher, 1993). Sibling interactions are powerful components of child development (Knott, Lewis &Williams, 1995) as their dynamic interactions have a large impact on socio-cognitive development (Howe et al., 2010). This unique source of environmental engagement has been linked with prosocial behaviours such as sharing, cooperation, and empathy (Pike, Iervolino, Eley, Price & Plomin, 2006). In their review on sibling relationships and mental health, Feinberg and colleagues (Feinberg, Solmeyer & McHale, 2012) stated that, although sibling relationships and experiences are an important context for development, they are still often ignored in research and interventions with the youth and families. The main research question of the current study was to investigate "*What is the living and lived experience of sisters growing up with an autistic preverbal sibling?"* An in-depth exploration of sisters' experiences, perspectives and needs aims to inform our understanding and promote new empowering types of support for siblings with and without disabilities throughout their lives. Without this fundamental knowledge, produced and disseminated by siblings themselves, the opportunities for wellbeing as well as their struggles will never be completely utilised or appreciated. Our goal is to understand factors that have not previously been given enough focus in the life of female adolescent siblings growing up with an autistic brother or sister with additional intellectual disability responding to the previous calls to explore more contextualised approaches to sibling research (Saxena and Adamson, 2013) and conduct more in-depth studies on siblings' first hand accounts of their experiences (Petalas, Hastings, Nash, Dowey & Reilly, 2009).

Outcomes for typically developing (TD) siblings growing up with a disabled brother or sister

A number of demographic factors have been examined in relation to the socio-emotional adjustment of siblings. The majority of past studies have concluded that factors such as the number of siblings in the family, the socioeconomic status of the family, and the gender and birth order of the non-disabled sibling has an impact on the adjustment of children growing up with a disabled brother or sister (e.g., Ferrari, 1984; Gold, 1993). These factors have often been perceived as ascribed and fixed in psychological research.

Some studies have found that there is an increased risk for adjustment difficulties in sisters in general population (Paker and Bronchie, 2004) and specifically in sisters of autistic siblings (Orsmond & Seltzer, 2009). Sisters have been reported to assume more caretaking responsibilities (Cridland, Jones, Stoyles, Caputi & Magee, 2015) as well as providing higher levels of support (Orsmond & Seltzer, 2000). Mates (1990) specifically found that female siblings and siblings from two-child families are at a greater risk for poor adjustment.

Kaminsky and Dewey (2002) and Verte, Roeyers and Buyesse (2003) have noted that siblings who live in families with more than two children are more likely to be well-adjusted than are siblings living in two-child families. The authors thus suggested that larger families may develop closer relationships and share care-taking responsibilities. Macks and Reeve (2007) tested 51 siblings of autistic children and 35 siblings of TD children, between the ages of 7 and 17, and reported that demographic characteristics are more likely to impact on a sibling of an autistic than a sibling of a TD child. Tomeny, Baker, Barry, Eldred and Rankin (2016) have looked at the impact of gender in relation to other family contextual factors. The authors administered a number of psychometric questionnaires (self and maternal reports) to 56 sisters and their mothers. Their findings indicated that sisters of autistic siblings with severe autistic symptomatology of unmarried parents are in higher risk to develop socio-emotional difficulties. Stoneman (2005) has suggested that siblings' role relations when one child has a disability follow a non-normative trajectory as it becomes more asymmetrical over time. He also emphasised the need to consider the age spacing, as this is often related to the lived experiences siblings might share such as having similar hobbies and going to the same school, etc. It is not clear if birth order has an influence on siblings' outcomes, but there are some indications that older siblings might be at increased risk to experience adjustment difficulties (eg. Rodrigue, Geffken, & Morgan, 1993). It is worthy noted that the majority of the studies looking at outcomes has often employed a conceptualisation of adjustment which has focused on the adverse siblings' outcomes), often failing to incorporating other child development dimensions such as the environmental settings in the life of siblings.

A rather limited information is available on the daily hassles and uplifts that siblings may experience in relation to their disabled brother or sister, both within and outside the family environment. Siblings' subjectivities and experiences have been described as holding particularly important information related to overall children's' sense of self and the formation of their social identities (Davies, 2014). Their subjectivities and experiences of siblinghood as well as the ways they negotiate their roles across different developmental stages remain under-investigated (Punch, 2008). Siblings' experiences are interconnected to a web of relationships across time and space with numerous important others within their family and social context (Kovshoff, Cebula, Tsai & Hastings, 2017). Edwards, Hadfield, Lucey and Mauthner (2006) emphasised the importance of the social context when considering siblings' experiences as they are culturally informed family roles, responsibilities, and obligations.

Similarly, McGraw and Walker (2007) emphasised that sociocultural boundaries might affect the way women experience sisterhood and their roles within wider power discourses. Their exploratory findings supported that sisters tend to accepting the gendered nature of family care and create a sense of moral enhancement related to themselves caring for their sibling with developmental disability. Nowadays combination of societal and legislative changes is positively reflecting on the lives of individuals with disabilities and their families. However, siblings of those with disabilities are yet to be involved in disability issues despite the fact that they play an integral role in the lives of their brother or sister. Yet understanding their lived experiences, professionals may discover new ways of formulating their case load, co-produce family solutions and enhance wellbeing of all family members.

Siblinghood and Autism Spectrum Disorders

It is well known that autistic individuals display unique characteristics in areas such as social communication, behaviours and/or interests (American Psychiatric Association, 2013). Most autistic children have at least one brother or sister (Allgood, 2010) and their atypical social interaction styles and increased needs may affect the development of sibling relationships. For instance, Petalas et al. (2012) propose several factors that can affect siblings of autistic children. These include a genetic predisposition to autism characteristics as well as environmental factors, such as coping daily with the social, communication and behavioural difficulties of autistic siblings. For many researchers the dominant question in siblings' literature has been the negative impact of the autistic sibling or have adopted a stress and copying approach. Descriptions of autism are often associated with a medical view of disability which has dominated disability research and policy assuming a competition of family life between typical and autistic family members. The potential of disrupted or damaging sibling relationships has often been over-emphasised by the previous research in siblinghood and disability research and adopted an individualised and marginalised approach. Meltzer & Kramer (2016) suggests that this focus is related to a long history of institutionalization of people with disabilities, as protecting siblings' wellbeing was one of the reasons that parents were encouraged by professionals to send their children with disabilities to institutions in the 1940s and 1950s. The focus of the current study is on the experiences, perspectives and needs of TD adolescent sisters of autistic children. Adolescence is characterised by a number of socio-emotional and attitudinal developments (Yurgelun-Todd, 2007). Siblinghood, through siblings' prosocial and conflicted interactions, propels further these developmental changes. Understanding siblings' internal and external experiences of siblinghood during their family and community interactions in adolescence may complement quantitative research focusing on developmental trajectories of psychological wellbeing. Understanding the relational depth of siblinghood experiences and needs in families raising an autistic child may inform family and social care policies. The latter is in line with NHS England priorities to improve access to services for autistic individuals and their family members.

Thus far, studies have largely been quantitative and include predefined categories, which focus on the outcomes in behavioural adjustment when examining family experiences. Previous qualitative studies have presented a number of negative sibling experiences due to physical aggression (Petalas, Hastings, Nash, Dowey, & Reilly, 2009) and verbal aggression (Angell, Meadan, & Stoner, 2012; Petalas et al., 2009; Ross & Cuskelly, 2006) which may link to feelings of external pressure and instability in the lives of typically developing siblings (Angell et al., 2012; Hoskinson, 2011; Smith & Elder, 2010). Mascha and Boucher (2006) interviewed fourteen TD siblings of autistic individuals and found that they experience great feelings of embarrassment due to their autistic siblings' behaviour. Some of the themes that have emerged from the qualitative body of research include: a feeling of responsibility and at the same time a need for more autonomy and space (Dellve et al., 2000); an expression of compassion and understanding towards their autistic siblings, and a feeling of anxiety due to physical violence

(Benderix, & Sivberg, 2007). Petalas et al. (2009) conducted interviews with eight TD siblings of autistic individuals whose ages ranged from nine to twelve. The authors reported that TD siblings expressed “divergent attitudes towards their brother with ASD” (p.393). Interestingly, while many participants reported struggles all mentioned positive qualities about their autistic sibling. For instance, respondents considered their sibling relationship as fun. Unfortunately, due to the short duration of the interviews (on average 26 minutes) the narratives provided do not offer great details. The majority of qualitative research has reported certain aspects observed in the narratives of typically developing siblings as atypical (Angell et al., 2012; Hoskinson, 2011; Petalas et al., 2009; Smith & Elder, 2010). This included being involved in their sibling's education or identifying themselves as their sibling's entertainers, caregivers and parents' helpers. We identified only one study by Gorjy, Field and Falkmer (2017) that does not use categorical classification of siblings' experiences (i.e., positive or negative similarly to Petalas’ study). In their study, 11 TD adolescents growing up with an autistic brother or sister were interviewed and described their lives as different when they compare themselves with their peers.

The narrow use of assessments such as self-reports and/or parental questionnaires and wide age ranges (e.g., 5 to 20-year-olds; Mascha & Boucher, 2006), the inclusion of autistic siblings with various IQ levels (Petalas et al., 2012) and/or different autistic symptomology make the previous findings difficult to interpret. There is a limited number of published research studies in which sisters of autistic teenagers provide their insight into their subjective experiences, attitudes and feelings. Thus, the rationale of the current study was to focus specifically on sisters who may be particularly exposed to undertake carer roles, and may experience higher emotional sensitivity and social isolation (Hastings, 2003; Kaminsky & Dewey, 2002; Macks & Reeve, 2007; Orsmond & Seltzer, 2009; Stoneman, 2005; Verte, Roeyers, & Buyesse, 2003). To our knowledge, no published research studies thus far reported adolescent sisters’ experiences and perceived needs of sisters growing up with a teenage autistic brother or sister with associated learning disability (but see Cridland et al. (2015) who included in her sample 3 Australian sisters who were growing up with an autistic brother). In our review of past literature, we argue that current research approaches in family research in autism hinder a focus on a deeper understanding of the human dimension of siblings' experiences beyond negative or positive outcomes. Our critique focuses on how current sibling research obscures attention to the conceptualisation of an alternative experience-sensitive informed framework from where autism research and interventions can be led in partnership with all family members. Despite the underlying assumption of pathology, the mixed findings so far do not suggest a strong negative effect for siblings growing up with an autistic brother or sister (Hastings & Petalas, 2014). Kovshoff et al. (2017) also suggest that negative outcomes found in some studies are "by no means inevitable or universal": (page 38).

Investigating the lifeworld of siblings in their situated context through 8 dimensions of human experience.

Autism has often been described as a threat to the well-being of family members. As a result, most researchers normally situate their research questions in relation to the adjustment difficulties siblings might face, often lacking a conceptual foundation which will allow researchers to attend to the spectrum of the family experiences and the meaning attached to them by siblings themselves, beyond the narrow view in which the autistic child is seen as the ‘problem’ in the family.

In order to move from the traditional narrative of vulnerability in family research in autism, we would like to contribute by offering the possibility of a shift from behaviour outcomes and a narrow focus on the sibling dyad to the human aspects of siblings’ experiences as portrayed through their situated context. The current study set out to contribute to the development of this area by using qualitative research to address family experiences and the meanings of these experiences that siblings encounter. As such, a phenomenologically driven stance may serve as an important foundation for guiding qualitative research in family studies on autism. Our approach is grounded in European existentialist phenomenology and builds upon the humanising care framework by Todres, Galvin and Holloway (2009). Although the philosophical roots of our conceptualisation are not new in the field of health psychology, we believe that it is appropriate to re-consider some of the implications of these perspectives within current discourses of siblings' research and practice. We are introducing a human science perspective in sibling research guided by the lifeworld of the participant siblings and recognise the value of uniqueness of personal experience in shaping endless possible developmental outcomes. Lifeworld constitutes everything within one's horizon of experiences such as relationships, places, time, burdens and opportunities (Ashworth, 2006). It stands for the experience of everyday living which is coloured with memories, happiness, joy, sadness, anger and so on for family members. To be concerned with siblings' lifeworld is to uphold a humanisation view when closely examining their experiential issues beyond focusing on behavioural outcomes. Through the lens of phenomenological psychology siblings are not viewed as part of a chain of mechanisms and the aim is not to discover frequencies and causalities, but to understand their complex relationships, experiences and needs at a human level which hold endless possibilities for wellbeing and suffering.

Building upon the humanising framework (Todres et al., 2009) we articulate eight dimensions that may help us to unfold the sibling experience and capture the depth and breadth of what it means to be a sister (Table 1.) Each row of the table represents aspect of the human experience and is followed by a definition that serves the purposes of our study.

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Drawn from a research history of psycho-medical approaches to determining the impact of having a brother or sister with a disability (Meltzer & Kramer, 2016 and Meltzer, 2018) siblings' experiences are often taken for granted and interpreted within Western medical model assumptions, providing very little about the meaning that they give to their experience of living with an autistic brother. According to Galvin and Todres (2013), returning to the elements of understanding what it is to be human by exploring these 8 humanising dimensions offers a base and foundation from which we may begin to examine the meaning that sisters give to their lived and living experiences more in depth. This framework is in line with Meltzer's (2018) recent call for more disability research studies in order to understand the ways disability is embodied and enacted within the sibling relationship. The emphasis of sisters' lifeworld may allow us to report on the sisters' own concepts of being.

Method

Participants

Twelve participants were approached and nine agreed to participate in the study. A purposeful selection method was chosen in keeping with the Interpretative Phenomenological Analysis (IPA) requirements to have a small and fairly homogenous sample (Crouch & McKenzie, 2006). The latter is shown in the results of the background testing in the results section. Participants were recruited from a community-based mental health unit for children and adolescents with autism. The family background questionnaire was completed. The inclusion criteria were as follows: (i) Typically developing (TD) sisters between 10 to 14 years old who had a sibling diagnosed with autism; (ii) severity of autism indicated by the Childhood Autism Rating Scale (CARS) was equal to or larger than 44 points (severe autism); (iii) developmental age (based on the revised psycho-educational profile (PEP-R) developmental score) was at least four years lower than the chronological age.

Background measures

CARS (Schopler, Reichler & Renner, 2002) is a 15-item rating scale on factors such as relationships to people, imitation, emotional response, body and object use, adaptation to change, visual response, and listening response. Each scale can be rated from 1 (normal for the age) to 4 (highly abnormal). Scores of 30 or above are considered indicative of autism. Findings of good internal consistency (.896, 95% CI .877-.913) and good inter-rater reliability (.796, 95% CI .736-.844) support use of CARS.

PEP-R (Schopler, Reichler, Bashford, Lansing & Marcus, 1990) measures functioning in seven developmental domains: imitation, perception, fine and gross motor skills, eye–hand coordination, nonverbal and verbal conceptual abilities. The child receives either a pass, emerge, or fail in each domain. The number of passes received is summed up and converted into a developmental score that indicates a functioning level in months. PEP-R demonstrates good internal consistency (Cronbach's alpha ranging from .91 to .93) and domain-total correlation (ranging from .75 to .90).

Short Sensory Profile (SSP) (Dunn, 1999) is a 38-item parent-report questionnaire that rates sensory behaviours on a five-point scale (always, frequently, occasionally, seldom, or never). There are seven subscales: tactile sensitivity, taste/smell sensitivity, movement sensitivity, under-responsive/seeking sensation, auditory filtering, low energy or weak, and visual/auditory sensitivity. A lower total behaviour score indicates greater impairment. Cronbach's alpha was calculated to examine the internal consistency for each section of the SSP. Internal consistency indicates the extent to which the items in each section measure a single construct. The values of alpha for the various sections range from .47 to .91.

Sample characteristics

All participants came from a lower middle class background according to their stated annual income and job description, having only one autistic brother or sister. Eight were from two-parent families living together and one from a divorced family living with her mother for the last six months. The average age of TD sisters was 13 years old (SD = 0.86) and 11; 8 years old (SD = 1.53) for the autistic siblings. Seven autistic siblings were males and 2 females. All sisters were fully biologically related to their autistic sibling. All but 3 sisters were older than their autistic sibling. See Table 3 below for siblings' demographics.

-----Table 2 around here-----

CARS scores of the autistic siblings confirm severely abnormal traits in all autistic siblings in areas such as relationships, imitation skills, emotional responses, and verbal and nonverbal communication. The average score of CARS (minimum 44 points) indicated that autistic siblings show intense autistic characteristics. The average PEP-R score (maximum 38 months) shows severe developmental delays in all areas, with the more severe problems reported in cognitive, preverbal skills, expressive language, receptive language, fine motor skills and social reciprocity. According to SSP scores, autistic siblings exhibit unusually high sensory processing patterns in auditory, visual, vestibular, oral and multisensory processing. These factors indicate difficulties in modulating daily sensory experiences and notable behaviour outcomes. These scores also indicate bad modulation, meaning that autistic siblings probably face difficulties in organising sensory inputs to create an appropriate adaptive response, such as responding to others or keeping up with the daily routines of the family. Only touch processing scores appeared to be close to typical performance. All autistic siblings attended special school and weekly private therapy sessions by health care professionals.

Semi-structured interviews utilising a mentalizing stance

Semi-structured interviews were chosen to allow two-way communication to explore the perceptions of siblings regarding their experiences. The questions were often directed at the participants' experiences, feelings and beliefs (Welman & Kruger, 2001). An interview guide was designed to include topics covering several domains, namely, knowledge and beliefs of autism, family interactions, family routines and holidays, school life, and peer relationships. The order of questions was flexible to allow the researcher to probe areas that arose during the interview. A 'mentalizing' stance was adopted in order to maximise opportunities to access the lived experience of the participants (Fonagy & Target, 2007). The mentalizing approach was used when sisters discussed specific episodes and events in their everyday experience with their siblings, and shared their related thoughts and feelings of self and of others in order to collect information around the 8 dimensions of sisters' lifeworld. The main strategy was to establish the important 'facts' of a specific episode from the sister's perspective. Details of actions and associated feelings were sought, followed by sensitive attempts to expand the story using a set of questions as guidelines. These attempts were characterised by questions elaborating on the events mentioned by sisters in order to allow for the sisters' internal world to be externalised through the interview process. By employing a mentalizing stance during the interviews and drawing from the work of Fonagy and his colleagues (2007) it was hoped that data would give the researcher a chance to have a closer look at the nature of systematic relationships among siblings in their families. The researcher's ideas were informed by the way the siblings on their own mentalize and report their experiences. The emphasis was placed on the meanings the siblings themselves attribute to their own and to other family members actions. It was hoped that the results would enable the researcher to understand the mental states by which siblings, implicitly and explicitly, interpret their own and others' actions of themselves and others which underlie behaviour. The concept of mentalizing would fit into the theory of constructivism in the sense that people work together in order to construct meanings. In order to explore the lived experience of a sibling of an autistic child, constructivism seems appropriate as the perception of the experience of an indvidual is constructed in the world we live in.

See Table 3 for an example of the questions used below.

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Data analysis

All interviews were recorded and transcribed verbatim in English. The data were managed manually using paper-based filing systems for recording coded segments. This method was employed due to the criticism associated with computer-based packages, such as the data becoming part of a forced and artificial framework that would impede creativity (Charmaz, 1995). We used Interpretative Phenomenological Analysis (IPA: Smith, Flowers & Larkin, 1999). In psychological research IPA uses small, purposively selected, and carefully situated sample. (Smith et al. 2009). TD sisters were seen as being actively involved in the construction of their personal realities. The data interpretation was facilitated by group discussions within the research team, and a credibility check of themes was conducted by the second author. A final consultation with the research team followed to discuss specific theme descriptions and select the most relevant quotes.

Results

IPA themes

The analysis of the complete interview data set identified four interrelated higher-order themes capturing sisters' experiences of living with an autistic sibling (see Table 3).

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'I don't live with autism, I live with my sister': Sisters' interactions with their autistic siblings. This thematic cluster includes descriptions of sisters' shared time together, as it relates to the subthemes of a myriad of feelings, a sense of togetherness when at home, acceptance of autistic behaviours.

A myriad of feelings

In relation to time spent together, all sisters expressed a range of feelings. For example, Maria talks about strong feelings of love:

> He is my companion; we grew up together. I can't imagine going one day to our room and not finding him there. He is my family; autism cannot change that. You need to love your family. It's part of who you are, you know.

Sometimes the feeling of guilt is expressed in relation to past behaviour in their childhood, when sisters tried to control their sibling's behaviour by even hitting them. All, except one sister, mentioned a range of negative emotions when describing their siblings' tantrums, including feeling "*sad*", "*bad*", and "*worried*", and that it is "*hard to see him biting himself*". Niki's reflection encompasses feelings of being "*rejected*" and "*sad*":

> She lets her anger out and can't accept what I say or do. It's like she is rejecting me every time I try to offer a solution. To see her bang her head or bite is hard. That makes me sad.

A sense of togetherness when at home

Discussions with the sisters were enlightening in terms of how much they enjoy spending time with their siblings playing construction games, with computers/iPads, running and cycling. They often explain how togetherness means love to them. Foteini explains that siblings spent time together because of love, but it is also what makes love stronger every day.

> My brother and I, we stay together all the time (smiles). Yes, we are like one. We stay together so much, we wake up at the same time, we brush our teeth at the same

> time. We are the kids of the house, you know. . .We love each other and we try to be united, this way our love grows every day...

Seven sisters share a room with their autistic sibling, so after school hours they spend the majority of their time at home around their autistic sibling. Most of the data provided evidence that the sisters attuned themselves greatly to their sibling by knowing the things that the sibling enjoyed, as well as the skills and positive attributes of the sibling. All the sisters provided extensive details about their siblings' interests and joys such as their favourite games, music, activities, food, and colours. Some sisters state that they like to teach their siblings new leisure skills, such as painting or cycling.

A positive view on differences

This subtheme captures the sensory and cognitive features of autism that are perceived as strengths by the sisters. While many sensory difficulties were reported as key area of everyday life struggles. Anne and Elena like to call those sensory processing differences "*super powers*" giving examples of how their brothers can "*eat too much pepper*" or "*shower with extremely cold water in the middle of winter*". For Susi, Niki and Foteini their siblings have fun reactions like the cartoons: "*for example he can make repetitive dance movements which make me laugh"*, "*has a talent for copying dance moves from TV stars*" and also have "*an eye for detail"* and have "*good taste in music*". This positive construction of sensory difference appears to be gleaned from direct verbal statements. For instance, Katerina explains:

> *My sister has a talent for completing beautiful colour patterns. She loves detail and she will never give up till all coloured boxes or tiles look the same. She has an elegant taste in music and she absolutely concentrates on the sound of the bass or drums. She has a great memory and although she can't read she knows how to find her favourite CDs or videos. I am not sure if that is autism or it's her. I would like to think it's just my sister. I don't live with autism. I live with my sister.*

'Always there for us, but often asking too much'. Sisters' interactions with their parents.

This thematic cluster includes descriptions on siblings' interactions with their parents, as it relates to the subthemes of *figuring out what works, sisters' parentification* and *parental expectations.* It is noted that the relationship with their parents is often conveyed through rich descriptions of every day home routines. When sisters spoke about their parents, they mentioned specific events in which their autistic sibling was starring – often displaying behaviour that was unsafe. All sisters express closeness to their parents and express appreciation of the efforts their parents make to accommodate their siblings' needs and report lots of success stories, and join effective problem solving. However, at times, they wish their parents were insisting less "*to fix things*" and "*teach my brother how to be normal*". The latter is also related to negative interactions amongst sisters and their parents, as it often generates conflicts.

Figuring out what works

This subtheme highlights the ways sisters have learned to respond to the autistic child's needs and in particular how parents have contributed to the knowledge of what works better in order to deal with a self-injury behaviour. Elena, for instance, reports:

> We have learned to operate in our own ways, sometimes we just need to look at each other and we know the 'signs' of what my brother needs. We always check for environmental and other triggers in order to prevent tantrums and self-injury behaviours. Mum is very good at being proactive and using photos to communicate with my brother while dad is good at releasing tension after a big tantrum or argument by telling jokes or putting on a nice TV show.

Sister's parentification

Parental expectation for the sisters to take on parental and protective roles was found in all interviews. Sisters reported conflicts with their parents as "*they will constantly remind you what you have to do, since your brother can not do it*" which most sisters feel it's "*annoying and* *unfair*". Susi reports an intense sense of responsibility since she must "*deal with it*" every time she has to babysit her brother or handle extra chores.

> My parents ask me to tidy up his mess, to take care of him…. Mum and dad are busy shopping, cooking or working…I need to stay back home with my brother and make sure he won't eat the peppercorns or play with the olive oil bottle. I need to make sure he is safe, fed and clean.

A common reason which seems to lead to sisters' parentification seems to relate to the difficulties fathers face in regulating and spending time with their siblings. Elena, for example, feels that her father is not consistent and attuned to the needs of her brother, especially during evening leisure time. In her words:

> It's hard for the two of them to spent time together. They both shout and fight and get exhausted. I think they don't really know how to play together. After a point, my dad gets tired, withdraws from my brother and demands that I keep an eye on him or play with him.

Parental expectations

This subtheme captures how sisters' experiences are influenced by parental expectations and requests. Antonita and Niki believe that their parents put lots of demands on both themselves and their siblings. As a result, much of their engagements with their parents revolve around arguing about settled rules and expectations. In particular, all sisters express the view that their interactions with their parents are negatively fueled by "*mum and dad are always trying to change my brother's behaviour*" or "*too many demands on me and my brother*". Sisters elaborate on their parents' efforts on 'normalising' their siblings' behaviours at home. Peggy gives a vivid example of a lunchtime routine:

> My parents can make things very difficult by trying hard to fix my brother the way they think he should be. My brother only eats certain foods; trying to constantly force him to eat something different creates a whole lot of tension in the house. Picture this:

> mum is pushing my brother to eat something new, brother gets upset destroying things at home, dad gets mad with my mum, then dad is asking me to tidy up the mess…I get mad and angry and wonder why do we have to impose our food tastes on my brother. It just does not work; it only makes things harder for all of us".

The above quotation is consistent with the overall desire of all sisters for acceptance of the autistic identity of their siblings.

‘Like a lonely fighter, tired but always on duty.’ Practical struggles of caring

This thematic cluster includes descriptions of siblings’ daily struggles, as it relates to the subthemes of *shortened sleep and frequent awakenings, issues with homework and study time at home* and as well as *limited access to leisure activities* often as a result of being day and night carers for their siblings. The richness of the following description sheds light on the daily burdens in sisters’ lives.

Sleep difficulties

All sisters described their sleep is impacted by their autistic sibling’s poor sleep patterns. In their descriptions, Elena, Mary, Foteini, Niki and Anne explain how it "*takes him ages to actually fall asleep*", "*he resists going to bed*", "*he wakes up 2 or 3 hours earlier than school wake up time*", "*has unusual sleeping positions and makes lots of noises*", "*makes rhythmic noisy movements while falling asleep*". All but two sisters characterise their sleep as poor due to room sharing and frequent night-time waking. Niki describes disruptions in her sleep pattern due to her sister’s behaviour; this affects Niki the morning after:

> It is so bad when I have to wake up early to go to school after dealing with her being awake in the middle of the night. My sister is up at least four to five times. She laughs and rocks in her bed. I cover myself with pillows and try to pretend I am sleeping, hoping she will fall asleep again.

Furthermore, sisters' showed great knowledge of why sometimes their siblings might not sleep. For instance, some of the sleep issues are linked to an unexpected event— "*for example, if we run out of his favourite yogurt dessert*". As Susi describes, this might be quite unpleasant:

> I end up going to the sofa almost every night. I might play some games on my phone till I fall asleep again or check photos on Facebook. My body aches if I sleep for more than two days in a row on the sofa. After a night in the sofa I feel tired and sleepy at school.

All sisters reported that they often have to act as night-time carers. Peggy says:

> He will bang his feet on the windows; he will move around all his toys. Sometimes, he will climb on the bookshelves and I am scared that he might hurt himself. I have to call him down. I can't risk him getting injured.

In most cases, mothers' interventions are needed to ensure that the sisters can have some sleep time.

Issues with homework and study time at home

Sisters expressed a range of concerns related to their homework including fights, lack of personal space and damaging school papers. Anne states:

> You can't go to school and say that your brother ripped the maths worksheet into pieces. It sounds ridiculous. I don't deserve that. I just want to be able to do what I have to do for school.

Limited access to leisure activities

This theme includes accounts about caring responsibilities, which are often compromised in their households. Most sisters made social comparisons to their classmates and peers, stating that they cannot have equal access to leisure activities. Foteini says:

> I rarely attend afterschool clubs or hang around with friends during the week. My mum will pick me up from school in a rush and we will both start planning the evening activities: shopping, cooking, bathing etc. Not much free time really. My classmates hang around during the week. When I finally meet them, I have a feeling I missed out some good fun while I was at home juggling with everything.

Anne attempts to explain why this is happening in her reflection:

> Mum or dad will ask me to take care of my brother or the house a couple of times per week. Other times, my parents will have to drive my brother to therapy and they cannot drive me to my friend's house or to a concert on time. Most of the time, mum will prefer us not to have visitors at home.

'I care about my brother and I want society to care about us.' Perceived sisters' needs

This thematic cluster includes descriptions on sisters' perceived needs, as it relates to the subthemes of *need for respite time* and *access to the ordinary*. Sisters' narratives prioritise their need to have "*more time just for the things I like"*, "*spend evening or holidays without extra caring responsibilities" and "connect myself with hobbies and people".* Most of the reported needs are related to access to age related activities such as participating in community outings with their peers.

Need of respite time

Sisters' personal accounts confirm a process of continuous lifelong demands and adjustment to the needs of their autistic sibling. These are characterised by periods of stress, frustration, and limited participation in activities with peers and/or extended family members. Sisters wish they had "*more time to see friends*", "*more time for outdoor hobbies*" and "*time to travel around the country with mum and dad like we did when we were younger*". Katerina and Foteini reveal that a sense of respite has been an important strategy for them to "*survive the daily responsibilities*" and exposure to their siblings' aggression. They also suggest that meeting with friends or spending time away at their cousins' house can be a great chance to "*recharge a bit, especially after episodes of tantrums at home*". Mary's reflections are in line with all the sisters' views:

> It works for me to see my friends or have a chat with my cousin on a day that my brother has been out of control, hitting and breaking everything in the house. Staying home and tidying up his mess or seeing him crying makes me feeling low. Having a break helps me forget about it and then, in turn, when I am back home, I just act normal and fresh. I am happy to be around him again.

Access to the ordinary activities

This theme describes the efforts sisters make in order to access community places with their families. Mary explains:

> My family has to plan and think carefully every step in before we visit my aunties' house, go to the playground or anywhere really. As if autistic people and their families don't belong in our community – everything in our community is made for people who know how to wait in long ques and can deal with noise or the not very discreet eyes of those who judge anyone different as less.

Niki, after sharing similar observations, adds:

> So many times my parents and I are discouraged from going to a restaurant, a supermarket or just the playground next to our house. It is disheartening to see that people still sometimes feel pity for my sister or don't understand that she is autistic.

Katerina epitomises her determination of her family by stating:

> People as well need to understand that he is different, not less. They need to be exposed to autistic kids and kids need to be exposed to them; this is ordinary life innit? My brother and I could do more things if society could accept him for what he is.

Access to services and information

This theme describes the wish of sisters to have more access to services which can offer direct support to them and their parents**.** Antonita explains:

> My brother attends a day centre for a few hours per week. I wish he could have access more programmes there as he is learning important skills and it's the only way for him to access community stuff, like fun activities or sports. My brother loves going

> there with his key worker. This gives me time to study while I know he is having fun and is experiencing the world outside the house in a safe and pleasurable way for him.

All sisters reflected on their need to know more about what the future holds for them. One sister was wondering if scientific teams abroad have already discovered a cure or new ways to improve communication in autistic people. All other sisters focused on assistance to get information around how to promote communication and sensory relaxation for their siblings, their siblings' prognosis for the future and services that will provide long term care, employability training and fun activities for the autistic siblings. As Peggy puts it:

> Apart from my parents I cannot think of any source of support for the future. You see, all services are made for children. After the age of 18 there are very limited services available for nonverbal autistic people like my brother. I would like to know what my options are and how I can live my life while making sure my brother is enjoying his life too… Autistic kids become autistic adults. Siblings' responsibility and love remains. I would like to know what choices I have to make for my brother and who can answer my questions about the future.

Discussion

The current study aimed to explore the lived experiences of sisters growing up with an autistic sibling. The qualitative methodology adds richness in the data collection and provides insight into the perceptions and lived experiences of nine adolescent sisters who are growing up with an autistic sibling. The novel combination of employing mentalizing techniques in semi-structured interviews facilitated the participants' expression of their experiences by equalising the research process and creating a space for both participant and researcher to reconstruct meaning regarding these experiences. The qualitative nature of this study provided TD sisters with an opportunity to express their meaning making of siblinghood experiences in an open and exploratory manner.

The current study provided us with rich descriptions that shape sisters' subjective experiences of siblinghood. The overarching theme of the findings was related to the environmental settings, the practical aspects of providing care and the qualities of their relationships in their everyday micro-contexts of home, school, neighbourhood and local community. Their narratives shed light on the ways these sisters navigate within a number of sociocultural norms (parental expectations to assist their autistic sibling to act normal) and boundaries (lack of respite time, lack of information and support services) as well as the ways they attempt to challenge these (an overall strong positive outlook characterised by feelings of acceptance, love and hope across all interviews).

While not generalisable to all TD siblings who grow up with an autistic sibling, the data are consistent with previous studies (e.g. Petalas *et al.*, 2009; 2012, Moyson & Roeyers, 2011; Angell, Meada, & Stoner, 2012). Sisters often made explicit reference to feelings of love while sharing fun activities (e.g. Kaminsky & Dewey, 2002; Rivers & Stoneman, 2003; Petalas *et al.*, 2009; Mascha & Boucher, 2006). These positive perceptions have been previously associated with the warm sibling relationship (e.g. Taunt & Hastings, 2002; Petalas *et al.*, 2009), which has implications for coping and adjustment in later life. These joyful experiences appeared to coexist with frustration due to the behavioural and sensory differences associated with their autistic siblings. The study identified struggles similar to those described in the studies mentioned above. At the same time, we shed light on three new challenges, namely, parental interventions that contribute to daily struggles during care taking activities, sleep issues and their impact on education.

Considering caretaking responsibilities, the only published study so far exclusively examining sisters' adjustment, by Tomeny et al. (2016), suggests that clinicians working with families with autism should be particularly aware of the functioning of the sisters due to the complex needs of the autistic child and the ongoing need for sisters to respond to their siblings' needs. This is in contrast to our current study, which indicates that sisters are successful in their care taking roles despite the complex needs of their autistic siblings and described themselves as "*kind guardians*", "*feeling connected*", "*showing compassion*", "*proud of offering help*" and consider that they show effective problem solving during everyday routines (see also, Chan & Goh, 2014). Gorjy et al. (2017) also confirm the great capacity of their adolescent participant siblings for deep feelings of love, empathy tolerance and acceptance of the autistic identity of their siblings. In addition, our results show that the struggle during caretaking activities arises mostly when sisters have to balance parental expectations (e.g. when asked to replace autistic behaviours and ask their autistic sibling to do things in a 'normal' way) or feel they have no respite time. Our study also underlines the importance of private time, respite time and recognising that sisters' access to ordinary activities with their peers is crucial for their sense of wellbeing. This is an important finding that may be considered in future family interventions or support planning during outings in the community.

In this study, we used the term parentification to describe tasks that were imposed on sisters by their parents. In contrast with previous literature in the field (see for instance Jurkovic, 1997) we recognise that parentification is a label with negative connotations that often adds a layer of dysfunction in families caring for a disabled child. Hence, we have chosen to use this term to describe caring activities that were not initiated spontaneously by sisters and did not entail aspects of reciprocal exchanges or caring activities that siblings initiate due to high love and moral feelings. On the contrary, when sisters are in an agency position to decide the type of support they feel is more appropriate (without parental involvement) during sleep, bath or lunch home routines they describe it in their narratives as "*giving help*", "*helping my brother is a* *normal thing*", "*a way to show love*", "*a family duty*". These words include a normative scope of helpful relations between siblings, in which sisters seem to feel comfortable, hence they should not be characterised as non- normative caring tasks. In our study, sisters acknowledged a number of practical struggles of caring, mostly associated with sisters' educational and leisure activities. However, a great number of caring activities were perceived by them as normal. This is in line with Meltzer's (2017) observations around the use of language young adult siblings used when framing one of the many ways they interact with their disabled and non-disabled siblings. In particular, the participants in her study used words such as 'help', 'helping out' and 'looking after' to describe what happens between them. Similarly to our study, the author noted that the use of everyday words such as help used by participants differ from the caregiving or carer narrative often found in previous literature or societal narratives of carer promoted by charities in the news (Hastings, 2016). It is possible that, at times, undermines the reciprocal nature of siblinghood in sibling dyads with developmental disorders.

There is currently no data on the impact of sleep, or indeed the lack of it, on the school experiences of TD sisters growing up with an autistic sibling. However the current data show that frequent and/or prolonged nocturnal awakenings can have negative impact on academic performance of the TD sisters. Moreover, sleep issues are clearly related to poorer daytime functioning of the sisters and their difficulty into completing homework without disruptions.

The emerging overarching essence of the experiential qualities that sisters described as part of their lifeworld in the themes presented in Table 3 is being a sister from both a position of vulnerability and agency. Sisters are presented as vulnerable (e.g. due to lack of leisure time, interrupted sleep) and at the same time they are in a position of agency (e.g., high ethic morals around diversity and equality in the society, exhibiting good problem solving skills in everyday home care taking tasks). We propose an alternative interpretation of the 'lifeworld-led care' model to embrace TD siblings' experiences growing up with an autistic sibling in holistic ways to recognise a range of possibilities and interconnections in the lives of siblings. We are thus placing their dynamic experiences on the continuum rather than prematurely categorising their experiences. A lifeworld paradigm holds the promise of uncovering the opportunities and constraints that exist in the siblings' lived experience and allows researchers, educators, charities and healthcare professionals to recognise felt experiences of wellbeing even in the mist of 'suffering'. It is suspending exclusively negative/positive focus in family research. The model of lifeworld may help us to understand qualitative data in a way that it will enhance our research and professional capacity for a sensitive approach to the experiences, needs and priorities of the siblings. It may complement biomedical perspectives and thus empower siblings' mental health through the humanisation of research and practice. The latter can be achieved by an emphasis on participatory and empathetic perspectives and a sense of wellbeing which may stand as a spectrum of possibility for families with an autistic teenager rather than a fixed category (positive or negative) of experience. We recognise that sisters' existence involves constraints and difficulties, along with joys and unique moments of warmth. For instance, sisters show great adaption to the day and night needs of their siblings and appreciate parental help. However they often feel frustrated with parental efforts to 'normalise' autistic behaviours. Another example is the fact that sisters want to spend time with their siblings and have fun, but also they wish they had more time for their friends or their hobbies. Lastly, sisters show elements of advanced moral development and act as advocates of autistic people in their local community, however they often feel tired or alone and wish societal structures could offer more support, awareness and acceptance. Researchers often begin their papers by describing the potential risks posed by growing up with an autistic sibling and draw tentative conclusions when their data yield positive findings. The challenge for researchers is to recognise these biases and conduct research which respects the autistic sibling. One way of working toward that outcome is to describe the lifeworld of siblings recognising the possibilities of vulnerability and agency along with the meanings they attach to their experiences rather than assuming a pathology narrative.

Limitations and future research

Our current study may not be representative of all siblings, partly due to factors described in this paper. In order to minimise large variability of the samples, we also introduced selection bias by including only adolescence female siblings who grow up with an autistic sibling with additional severe learning disability, all coming from similar socio-economic and cultural background. We recognise that these sisters' experiences might not be typical of all siblings growing up with an autistic brother who is verbal, attends mainstream school, had a late diagnosis or when one or both siblings are in adulthood. Further research examining the lifeworld of different siblings' age, gender, cultural context compositions is needed before we aim to map developmental trajectories of siblings' mental health outcomes.

The current study presented several novel and rich findings regarding sisters' involvement and practices across different places (home, school, neighbourhood, local community). Further research, taking a more context-sensitive approach is needed, looking at siblings' geographies of care.

Furthermore, the results of the current study suggest that the sensory differences and sleep disturbances are clearly an important area for further research in relation to the individual as well as family experiences. Poor quality and quantity of sleep have been shown to negatively affect daytime functioning, cognitive and social development, as well as general mental health (e.g., Ashworth et al., 2016). Thus it is important to examine these negative environmental factors further and promote better sleep support to families raising an autistic child having in mind the sleep needs of all family members.

To avoid the tragedy narratives and offer a more balanced view around siblings' lives researchers should adopt a stance that will allow them to attend to the spectrum of experiences of siblings across the lifespan. By understanding the way sibling experiences change over time, adult siblings’ contributions to the lives of their autistic brothers or sisters can be better supported (Tozer & Atkin, 2015).

Although the current shift to a more inclusive qualitative and mixed method methodologies in siblings’ research is visible, the voice of autistic people remains excluded, thus contributing to the de-evaluation of the views of disabled people rather than improving their quality of life (Munger & Mertens, 2011). For autistic people, like all people, family interactions are the centre around which the narratives, we ourselves, come to know, as we develop. So, why do we exclude them from siblinghood research? One possible explanation is offered by Milton (2016) who drew on Young’s popular work of the ‘five faces of oppression’ (Young, 1990) in order to help us understand how these have been historically applied to autism research. For Milton, concepts of her theory such as marginalisation, powerlessness, cultural imperialism and violence towards autistic people are the roots of ableism in autism research and clinical thinking. In line with the latter, we echo Meltzer’s and Kramer’s (2016) voice who argue for the application of more materialist, feminist and inclusive perspectives in siblinghood and disability research. While examining that the inductive reasoning and individual experiences matter and inform future research and the design of sibling support models, the siblinghood experiences of autistic people may also enrich the ways we conceptualise disability in family research and inform further social and mental health policies. In order to achieve that a useful step would be to merge feminist and critical disabilities studies in the psychological research of siblinghood experiences in autism.

An existential view of wellbeing: Agency and vulnerability as equal potentials

There are very few studies in siblings' research which have utilised a philosophical, social or psychological stance when considering sibling's experiences. In line with the lifeworld framework we proposed, this study drew our attention to sisters' humanising dimensions – such as the need to feeling respected, secure, valued, involved and informed - in the data presented above. With this study, we echo Gorjy et al (2017) who acknowledge explicitly the strengths, abilities and resourcefulness of teenage TD siblings. This study found an equal number of the possible struggles and opportunities for growth in the life of sisters of an autistic child as shown above in- Table 5. This is in contrast with previous research emphasising on vulnerabilities (for instance see Benderix and Sivberg, 2007) or siblings' adjustment problems (Hastings, 2003)

-----Table 5 around here------

In examining the everyday lives of sisters in its qualitative character, our results indicate a strong need to acknowledge sisters as active agents who take many decisions at home, whether or not they comply with their parents and environmental settings. Affirming the sisters for their caring contribution/s in their family and moral sense driven by ideas such as inclusion and acceptance is important for their self-esteem as well as the advancement of positive narrative around the families with an autistic child. In our study sisters reported their environmental settings and relationships in their families, schools and their local communities. We found that the descriptions elicited from them about their day-to-day experiences when adopting a lifeworld approach across all stages of this study (conceptualising the topic and research question, interview agenda and interpretation of data), experiences of wellbeing and struggle went beyond the contribution of the presence of autistic behaviours. This message is important for both parents and professionals, as it moves away from the notion of the pathologisation of the families of autistic children (without lessening the hardships faced by sisters), and/or the narrow focus on the autistic child being excluded from other family members. This may contribute to an emerging change of the negative narrative relating to families living with an autistic child with associated learning difficulties. A lifeworld approach attempts to capture personal lived experience in sisters' terms, as opposed to prescribed by existing scientific or personal presumptions based on the psycho-medical model. The current framework was developed to directly oppose and replace the pathologising narratives of previous research and the casual conditions of siblings' behaviour where the presence of an autistic sibling is examined as the cause of 'suffering'.

The emerging overarching essence consisting the experiential qualities which sisters described as part of their lifeworld in the themes presented in Table 3 is being a sister from both a position of vulnerability and agency. Sisters are presented as vulnerable due to lack of leisure time and interrupted sleep but at the same time present themselves in a position of agency with high ethic morals around diversity and equality in the society, exhibiting good problem solving skills in everyday home care-taking tasks. We thus offer an alternative interpretation 'lifeworld-led care' model first introduced by Galvin and Todres (2013), and argue that it can serve as a valuable framework of understanding siblings' experiences growing up with an autistic sibling in a dynamic way avoiding categorisations of their experiences.

---Table 6 around here---

A contextualised understanding of day-to-day interactions of their lifeworld, beyond the contribution of the presence of the autistic sibling may widen the professionals' perspectives and possibly be translated by both quality improvement and cost containment. Acceptance and strength-based family support schemes may be applied proactively in schools and family therapy centres where sisters may discuss their experiences. Healthcare practitioners should approach family members sensing the uniqueness of their personal journeys, enhancing the ability of sisters to understand interpersonal difficulties as part of human life and development instead of over-focusing on behaviour adjustment and skills training.

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Table 1 Dimensions of humanisation and their meaning.

Insiderness	Understanding sisters’ hopes, fears, struggles during every day routines and the myriad of different feelings that may co-exist. Understand their value driven efforts to care taking of their siblings and promoting acceptance in the community.
Agency	Promoting sisters’ abilities to take decisions with researchers, parents and clinicians around their involvement in qualitative inquiries.
Uniqueness	Sisters’ experiences are unique and do not necessarily fit under a diagnostic umbrella. They should be seen as individuals with many identities such as female, student, friend, sibling, daughter, etc.
Sense making	Sister’s giving meaning to the world does not mean seeking for exclusively positive or negative experiences.
Personal journey	Practitioners should be proactive on facilitating each sister’s personal journey planning and aspirations.
Sense of place	Sisters should feel welcomed, safe across home, school and wider community. Chances to celebrate their identities and share their experiences should be created in the community as a mean of empowerment.
Embodiment	Each sister’s experience of living and being beyond narrow definition of themselves. Enabling positive personal identities relevant to their challenges and strengths.
Togetherness	Sisters should have access to people they value and feel that they can share their worries/disagreements or ask for help as well as to those who can share fun and intimate moments.

Table 2 Participant sisters' family demographics

TD sisters' pseydoname	TD sisters' age in years (y)	Autistic sibling's diagnosis	Autistic sibling's gender	Autistic sibling's age years (y)	Marital status	Family SES^3	Total Number of siblings in the family
Katerina	14 y	ASD^1, LD^2	Female	12 y	Married	Lower	2
Peggy	12 y	ASD, LD	Male	10 y	Married	Middle	2
Mary	13 y	ASD, LD	Male	12 y	Married	Middle	2
Foteini	13 y	ASD, LD	Male	14 y	Married	Lower	2
Anne	14 y	ASD, LD	Male	11 y	Married	Lower	2
Susi	12 y	ASD, LD	Male	10 y	Divorced	Lower	2
Niki	12 y	ASD, LD	Female	14 y	Married	Lower	2
Antonita	14 y	ASD, LD	Male	10 y	Married	Middle	2
Elena	12 y	ASD, LD	Make	11 y	Married	Lower	2

Note: ASD^{1}refers to Autism Spectrum Disorder, LD^2 refers to Learning Disability, SES^3 refers to Socioeconomic status

Table 3Types of mentalising questions and examples

Questions	Example
Descriptive	What do your sleep routines entail?
Narrative	Can you tell me about your parents?
Focusing to the others	Can you explain why he (she) did that?
Reconstructing questions based on events brought up by the participants	What would need to happen for him (her) to feel differently? How would you need others (parents, friends) to think about you so you feel differently?
Focusing to one self	What did it feel like for you? What were your thoughts at the time it happened, and what did you do?
Comparative	How does your experience of being a sibling of a brother (or sister) with Autism compare to the experience of others (friends, cousins etc)?
Prompts	Can you tell me more about that please?
Probes	What do you mean by <hard>?

Table 4 IPA master themes and sub-themes

Master theme	Sub-ordinate themes
'I don't live with autism, I live with my sister'. Sisters' interactions with their siblings.	A myriad of feelings A sense of togetherness at home A positive view on differences
'Always there for us, but often asking too much'. Sisters' interactions with their parents	Figuring out what works Sisters' parentification Parental expectations
'Like a lonely fighter, tired but always on duty'. Practical struggles of caring	Shortened sleep & frequent awakenings Issues with homework/study time at home Limited access to leisure activities
'I care about my brother and I want society to care about us.' Perceived sisters' needs	Need for respite time Access to the ordinary activities Access to services and information

Table 5 A sense of both agency and vulnerability in sisters' lives

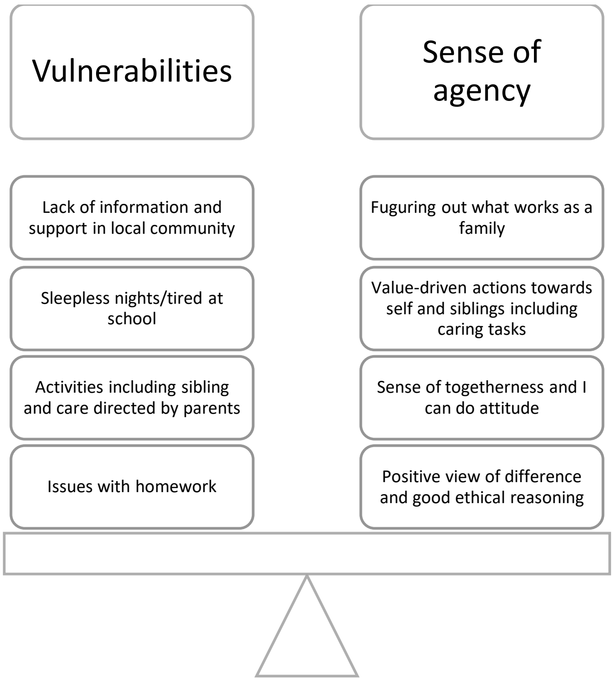

Table 6 A lifeworld experiential context for considering sisters' wellbeing

Insiderness vs Objectification	To be human is to experience life and the important relationships in life in relation to how humans understand the world. The world is experienced through mood, feelings and personal meaning – meanings which shape humans' actions and decisions. Looking at sisters from a relational and strength approach rather their behavioural phenotypes ensures that they are not viewed by researchers, healthcare professionals and charities as a list of fragmented risks and issues due to their autistic sibling. Understand their value driven efforts to care taking of their siblings and promoting acceptance in the community.
Agency vs Vulnerability	Sisters seem to be agents of themselves from a young age in their relationship with their siblings. A sense of agency is often closely linked to wellbeing as humans can take responsibilities, exercise choices and form relationships that they feel comfortable with. When passively dependent on parental choices, healthcare professionals and services, siblings might not be able to voice their needs or participate in the care of their siblings in the ways they feel comfortable. For instance, sisters might experience wellbeing when the clinical services proactively engage them in their family planning, empowering them to choose the role they want to play in the family system. Vulnerability might be experienced when healthcare services for adult siblings emphasize the individualisation of their services, providing parents and siblings with individualised positive behaviour plans without consulting the family, full of technical jargon, making them difficult to sustain.
Uniqueness vs Homogenasation	To be human is also to actualise a self that feels unique. Researchers, healthcare practitioners and charities have often named siblings of autistic people a risk group or characterised them as unpaid carers or everyday heroes. Yet, we know little about what it is like to be labelled as member of such a group. In our study sisters did not label themselves in any other way than siblings, friends, students, daughters and cousins. One participant replied that she does not live with autism, she lives with her sister. It can be argued that labelling is a form of objectification, as humans are 'forced' to be part of statistical category while their uniqueness is not fully considered. Although these categories may often attract positive attention by society and enhance advancements in policy making, it implies a de-emphasised sense of the unique identity of the siblings and their right to choose to act differently. What about siblings of preverbal autistic people who have declined a day and night caring role, but still want to have an active supporting role in the life of their siblings? What about sibling dyads where no sibling has a learning disability yet both siblings might need proactive support and access to information but they don't get it because they don't fit any diagnostic umbrella? The sisters in our study defined care from a more relational perspective. For example, they recognised that they offer help in the house and with everyday family routines. Offering help to their mums and siblings was related to a duty towards their beloved ones and less as a consequence of disability in the family.

Sense making vs Loss of meaning	To be human is to care about the meaning of your events and experiences. Sisters may look at these experiences through their personal lens rather than official representations of disability related risks and problems. This may enrich clinicians' and researchers' perspectives. Researchers and practitioners should recognise felt experiences of wellbeing, even in the mist of suffering, and contribute to a positive narrative for all members of the family. The sisters of our study shared their meanings of siblinghood which, despite practical day-to-day struggles (e.g. sleep), had a positive outlook; a reminder that the way we think and speak about disability matters and affects siblings, public views and policy.
Personal journey vs Loss of personal journy	Sisters positions themselves in terms of their lived (past), living (current) experiences as well as future hopes, fears and aspirations. It should be recognised that their experiences of autism in the family is only one part of life. Practitioners should be proactive on facilitating each sister's personal journey planning and aspirations in their preferred directions. Inductive / Idiographic reasoning matters and may inform current and future siblings' research and support services.
Sense of place vs Dislocation	Sisters should feel welcomed, safe across home, school and wider community. It is important that parents and teachers are sensitive to their needs and take into consideration the side effects of day and night care taking such as lack of sleep or lack of time. The spatiality of reciprocal siblings' exchanges and care matters. Sisters interact with their siblings not only at home but also in their outings in the community. The sense of place may affect their parents' expectations or the autistic siblings' behaviour due to sensory and other difficulties. Further autism acceptance in the community may provide less frightening and pressing experiences for both siblings and a comfortable sense of place.
Embodiment vs Reductionism	Each sister's experience of living and being beyond narrow definition of themselves imposed by researchers, clinicians and public views. Enabling positive personal identities to emerge through living with an autistic sibling is crucial for their wellbeing. Attention needs to shift from psychological adjustment outcomes to their perceived needs and goals as self-organizing, self-maintaining, and their role as embodied agents
Togetherness vs Isolation	This study highlighted a variety of positive experiences which indicate that we need to update our understanding of sisters being burdened by their autistic siblings. Sisters appreciate and value the time they spend with their siblings and at times they would like to have more access to people who can share fun and intimate moments (classmates, peers) and people who can offer them information and help (parents, teachers, healthcare professionals).