Title: In their own words, in their own photos: Adolescent females' siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister.

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Abstract: Thus far very little research has focused on siblings in early adolescent years growing up with an autistic sibling. Adopting a community-based participatory research (CBPR) approach, 11 typically developing sisters actively collaborated in the study to collect and analyse data as well as disseminate their experiences, needs and perspectives in their local communities. This is the first study to use a modified Photovoice methodology which provided typically developing sisters an active participatory role. The results highlighted the feelings, needs and thoughts the sisters expressed in their role as siblings, friends, but also as students and citizens with a passion for advocacy, and limited support in the community due to unhelpful attitudes of members of their community towards autism.
The findings indicated that the current method used can successfully co-generate research findings with family members by ensuring pathways for engaging local community. This is crucial in shifting the balance between vulnerability and resilience in families raising an autistic child. Furthermore, when knowledge about the lived experience is drawn directly from the perspective of the actual people (siblings) involved in the phenomenon (siblinghood and autism), a more appropriate, responsive and need-fulfilling strategy of supportive and proactive support systems can be initiated.

Introduction

Sibling interactions are important and powerful components of child development. Their longitudinal interaction and continuous relationship influence cognitive, social and affective development (Howe & Ross, 1990; Smith, 1990). Importantly, the quality of sibling relationships has been found to be a robust predictor of mental health diagnosis even 30 years later (Waldinger, Vaillant & Orav, 2007). The majority of past studies have examined 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 in relation to the psychological adjustment of children growing up with a disabled brother or sister (e.g., Ferrari, 1984; Gold, 1993). In recent years, the diagnosis of autism has been on the rise, prompting a simultaneous increase in research studies in family experiences of siblings' growing up with an autistic brother or sister (Hansen, Schendel & Parner, 2015). This study aims to report the methods and the results of a series of collaborative efforts between sisters of autistic children with additional learning disability, academic researchers and representatives of the sisters' local community.

Methodological considerations of past research and the need for collaborative research

There is a long history of family research in developmental disabilities, but until recently the perspectives of siblings did not feature extensively. In recent years, several studies included siblings' own views, for example with quantitative self-report and interview studies on the adjustment of siblings with diagnosis of autism (hereafter 'autistic') (e.g. Orsmond & Seltzer, 2009; Petalas, Hastings, Nash, Dowey & Reilly, 2009). Kovshoff, Cebula, Tsai and Hastings (2017) noted that previous psychosocial adjustment estimates which relied on parent-report might differ from more recent studies which use self-reports (see also Hastings & Petalas, 2014). This highlights the importance of asking siblings directly about their experiences.

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Despite the inconsistencies in results, sibling research in autism has, for many decades, laid emphasis on poor adjustment outcomes for siblings of children with developmental conditions such as autism and learning disabilities versus strengths. Kovshoff et al. (2017) also suggested that negative outcomes found in some studies are "*by no means inevitable or universal*" (page 38). Even more promising, a few research studies have identified the positive impacts of growing up with an autistic sibling (see, for example, Verté, Roeyers, & Buyesse, 2003).

There have been further encouraging developments in autism sibling research, including research that examines siblings' experiences directly using semi-structured qualitative interviews from a strengths-based approach (Gorjy, Fielding & Falkmer , 2017) and photo elicitation interviews (Latta et al., 2014). While researchers posed questions using siblings' photos to encourage children to talk freely and explain more about their experiences, siblings were not actively involved in any stage of the research other than discussing their photos with the researcher. Furthermore, most qualitative studies only engage siblings in short interviews from 25 minutes (e.g. Petalas, Hastings, Nash, Railly and Dowey, 2012) up to 45 minutes (e.g. Angell, Meadan and Stoner, 2012). Background behavioural data on the autism diagnosis, severity and sensory profile of the autistic siblings are rarely provided, thus making it difficult to cross compare with other research studies.

While Foden (2007), similarly to many authors, has stated that TD siblings face the "daunting" task of forming a "healthy" sibling bond, Meltzer (2018) recently challenged this position by providing accounts of the various ways siblings with and without disabilities can successfully engage in supportive and conflictual talk, and seek connections with each other. Meltzer and Kramer (2016) have called for research to explore ways we may use the knowledge siblings have acquired at home from their brother and sister, to promote inclusion or challenge ideas of what is 'normal' in society and build local capacity in their

communities. This has further been outlined in the Siblings Embedded Framework, which calls researchers to keep an open stance and move from autism deficits and consider family life events more broadly when looking at experiences of siblings in different environments (Kovshoff et al., 2017). More research using qualitative methods that directly seeks to capture the whole spectrum of their experiences has been recommended (McHale, Updegraff & Feinberg, 2016). As mentioned earlier, until today, even when visual methods are adopted, the researchers have been at the centre of decision making without evidence of siblings' involvement such as sharing and discussing their stories, emotions and experiences in self-facilitated group settings. To our knowledge, there are no studies that included siblings' views about what should happen to their findings and how and where they should be disseminated. The latter confirms the lack of effort to involve siblings across all stages of research and in post-research action plans, restricting the studies to the academic research community.

Following current trends in autism research the quest to understand autism is dramatically and paradigmatically shifting (Wright, Wright, Diener & Eaton, 2014). Accordingly, autistic people and their families could and should offer their understanding of autism through sharing their lived experiences in participatory research approaches. Participatory research methods enable researchers to connect with relevant communities to achieve shared goals which are relevant to family members' lives and thus likely to have a positive impact. The development of collaborative practices within the local community may enable researchers and participants to further contextualise findings within their real-life settings and, thereby enhance the translation of findings into practice and future research requirements (Carrington, Uljarević & Roberts , 2016; Parr, 2016; Parsons & Cobb, 2013).

Therefore, it is imperative that a more progressive research agenda with clear participant-focused designs and methods are adopted.

The current study

The current study was conducted in Greece, which has been a member of the European Union since 1981. The country shares similar social norms, ethical values, political systems and technologies to those typically found in the Western countries. Siblings in Greece, similarly to the rest of the world, are not identified or supported by local educational authorities and schools, and their needs and strengths across their lifespan remain largely overlooked by service providers and policy makers.

This study aimed to employ community-based participatory research (CBPR) to investigate sisters' experiences in a power-sharing, multi-step process, largely co-established with sisters themselves. See Figure 1 below, for a summary of actions taken to create opportunities for sisters to be involved across all stages of the current study.

………. **Figure 1 around here…..**

This study is in line with a lifeworld-led framework; hence our efforts are rooted in a value-based humanistic view of sisters' experiences – such as the need to feeling respected, secure, valued, involved and informed (Pavlopoulou & Dimitriou, 2019). This framework is in line with an explicit social disability shared ethos, contributing to a move towards new ways of thinking about sibling and autism research that do not rely on existing 'deficit-based' narratives. Our study approach is also grounded in a holistic perspective that allows sisters to consider freely the interplay of factors across their family, school and local community when considering their siblinghood experiences. Such a holistic approach also fits with the phenomenological stance of this study. The use of sibling-driven visual methodologies aimed

to give sisters the flexibility and freedom to select what to depict and what is important to them using technology (cameras, iPads) that they may already have been interested in, used, and enjoyed.

Methods

Whose voices are represented in this study?

The wide variability in sibling research findings indicates a need to identify the demographic status and birth order that may influence siblings' experiences and needs (Tudor & Lerner, 2015). This need is particularly important for sisters, given their potential caregiving roles within families. In addition, presence of learning disability has been found to be another important factor to consider when examining the experiences of TD siblings. Siblings of brothers or sisters with learning disabilities are important but understudied family members (Shiver & Dykens, 2017).

For this reason, the current study aimed to include a fairly homogenous sample of sisters to present what constitutes the experiences of sisters with particular characteristics. The study involved sisters who were growing up with a younger or similar age autistic brother or sister, with additional learning disability, diagnosed by a professional registered with the Greek National Health System. In many sibling studies, the majority of participants have been part of high-income families (see for instance Pilowsky, Yirmiya, Doppelt, Gross-Tsur & Shalev, 2004). In the present study, all sisters came from lower income families.

The sisters were chosen from a list of sisters from three boroughs with the help of the local autism association in X, after completing a demographical questionnaire developed specifically for this study. Finally, the participants were chosen on the basis of their willingness to share their experiences with groups of siblings and their community.

Ethical Considerations in Photovoice

The Ethical Review Board of XXX and the board of Trustees of the city of a local branch of the National Association of Parents and Friends of Autistic people in Southern Greece approved the study and each participating sister in the study and parents provided their consent. Since sisters contributed considerably to the modification of the visual methodology, by choosing to use photos as their primary mean of data collection, the authors successfully applied for a second ethical approval once methodological steps were clarified by the group of sisters. Importantly, the procedures included sisters training in how to be ethical photographers (e.g. how to take consent and discuss the purpose of the photo taking/photo collection with the people appearing in them and not to force them to take part). Participants were asked to consent for their photos and narratives to be presented in the local newspapers and/or websites or academic publications. The autistic siblings were also asked for their permission using visual consent forms. All parents and siblings were given different options to decide whether and how to use the photos (e.g. blurred photos for academic submission purposes and/or for conference presentations or no photos at all - just the narrative accompanying the photo). The materials included in this publication and during the study procedures have been approved by the parents and siblings.

Background characteristics of sisters and their autistic siblings

All sisters were fully biologically related to their autistic sibling (Table 1). The households fell into socioeconomic group (NS-SEC) categories 4 to 6 using the employment information provided by parents (Office for National Statistics, 2010). Sisters lived within three different urban and rural areas of X (removed for blind review), and each had only one brother or sister (all of whom has a diagnosis of autism with additional learning difficulties). Nine of them were from two-parent families living together and two of them were from a divorced family

living with their mothers for the past two years. The mean chronological age of the sisters was 14.27 years old (SD = 1.33) and 12.6 years old (SD = 1.62) for autistic siblings. The autistic sibling (female = 2, male = 9) attended special schools and were registered for evening therapy from 4 to 10 hours per week. Two autistic siblings were on medication for sleep, anxiety and attention difficulties.

- Table 1 about here -

All TD sisters attended their local mainstream school, which was different from their siblings' school. The Childhood Autism Rating Scale (CARS) was also administered to both TD and autistic siblings (Schopler, Reichler & Renner, 2002). CARS 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. The minimum scores for autistic siblings on the CARS was 44, while sisters scored below 20.

The Psychoeducational Profile- Revised (PEP-R by Schopler, Reichler, Bashford, Lansing & Marcus, 1990) was administered to the autistic siblings to confirm the presence of a learning disability. PEP-R 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. Autistic siblings average PEP-R score (M=28.08, SD=3.2) showed developmental delays, with the more severe problems reported in cognitive, preverbal skills, expressive language, receptive language, affective expression and social reciprocity.

Parents also completed the Short Sensory Profile (SSP) (Dunn, 1999) to describe the sensory profile of their autistic child. SSP 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. According to the results on the SSP 9 autistic siblings exhibited higher sensory processing patterns in auditory, visual, vestibular, oral and multisensory processing. These indicate difficulties in modulating sensory experiences in daily life. Touch processing scores appeared to be close to typical sensory performance scores for 8 siblings.

Utilisation of Photovoice Methodology combined with interviews and focus groups

The study involved 7 phases, facilitated by the first author and decided on by the TD sisters. Four sisters offered to take turns as note takers during group meetings. Group meetings ranged from 1.5 hour to 2.5 hours over a period of 36 weeks. Individual interviews lasted from 45 to 70 minutes. In total, 39 meetings between the first author and the sisters took place over a period of 9 months.

An outline of the Photovoice procedure is provided in Figure 2 below, followed by a short description for each Phase.

Figure 2 around here

Phase 1: This stage included initial introductions, ice breakers and ethics training around the use of photography for research purposes. Sisters met with the first author to discuss and agree on the ways they will approach the central theme (sisters' experiences) and the research process. The main objective was turned into the research question of this study namely: **What are your experiences, perspectives and needs in your family, school and local**

community as adolescent sisters of a preverbal autistic brother or sister? Sisters were given several options in order to collect their data (including drawings, storytelling and clay). Sisters preferred the use of photographs and then the researcher and sisters decided on the included 7 phases of a Modified Photovoice version. Choices regarding recording methods were made. Some sisters preferred to use their own iPad or phone cameras, while others used the administered digital cameras. Sisters were told that there were no expectations as to what photos they decided to take. In order to minimise potential confusion, two examples of short photo tasks were given. During these tasks, sisters had the opportunity to train in critical aspects of Photovoice such as visualising and mapping photo material related to a research question. The first author introduced the sisters to a set of visual tools order to encourage them to think about how photographs may tell their siblinghood stories and how they may be working on ways they could voice their lived experiences of growing up with an autistic sibling.

TD sisters were also asked to choose a pseudonym by which they wished to be known in the presentation of the results. They wrote the name on a piece of paper and were instructed to photograph it for the first frame. This way, each participant's material was matched to the correct name and the participants also had a chance to practise using the camera. Ethical responsibilities regarding the appropriate use of the camera were also addressed in this phase during the "Being an ethical photographer" section. Furthermore, sisters brainstormed on a worksheet their ideas on whom they should recruit, based on who, they felt, should know about their experiences. Sisters identified a number of academic, therapy, teacher and parents' groups which, later on, volunteered to accommodate sisters' exhibitions and also attended the sister- led events.

Phase 2: The following instruction was given: "*Take photos for a period of 3 weeks that tell the story of what it means to be a sister of an autistic preverbal brother or sister.*" Sisters

used the cameras to capture their everyday life and filled in a photolog for each picture for 3 weeks. They also kept diary notes for a week. At the end of week one and two, a letter was sent home to remind the participants of the ground rules discussed in phase 1, as well as whom they could contact, their right to withdraw, etc. Phone calls were made at the end of the three weeks to arrange interviews. In addition, at the beginning of week 2, sisters decided to bring up to 15 photos, each from their family/personal/school albums that might represent important experiences that could not be captured during the research period.

Phase 3: Individual face-to-face semi-structured meetings were conducted to guide sisters to strengthen and personalise their individual messages prior to the group meetings. Each meeting was largely flexible and directed by the sisters' ideas in order to minimise the researcher's bias. The sisters worked in a quiet room provided by the X Association. Three main sets of questions that were part of a flexible dialogue – the content (what), the purpose of creation (who, when, how) and interpretation (why) – helped the researchers understand the photos and the sisters to create a personal story around each photo in order to clarify ideas and also to understand the roots and the consequences of the targeted issues captured in the photos. Closed questions were only used when a sister was very shy, especially at the beginning of the meeting. Sisters were provided with A3 paper, coloured markers, a printed set of their photos and photo log diaries, scissors and glue in order to create a collage of salient aspects of their siblinghood life. This activity offered an opportunity for participants to create visual stories about how they felt about different aspects of their everyday siblinghood experiences at home. The first author kept field notes on the categories each sister created, and the explanations/comments/feelings offered by them. Then, she reviewed the transcripts and the photos multiple times to become familiar with each sister's story.

Phase 4: It was suggested to the sisters that two small groups should be set up to ensure that there was enough time for each sister to meaningfully express her views and experiences.

This was agreed. Each group selected a leader amongst themselves. The sisters decided that the two groups should have shared time at the beginning and the end of every meeting. Structured photo selection and guided dialogue were employed. According to these, each sister was asked to select five to ten photographs that could best answer the research question. The dialogue around the photographs was guided by a Photovoice technique called 'SHOWeD' (Catalani & Meredith, 2010) in order to help them contextualise and organise their personal photo descriptions. The letters of this acronym correspond to a specific question prompt (see Table 2 below).

Table 2: SHoWED protocol

This format allowed the sisters to challenge each other in a critical and consistent manner when analysing the content of their photographs.

Phase 5: The sisters decided to bring an additional set of photos that further represented their living experiences as a result of discussions that took place in this phase The sisters then contextualised the new set of photographs repeating independently the procedure described in Phase 3 (contextualising and narrating their photos and explaining their importance through group dialogue). Then they worked together to codify the themes emerging from the photographs, as well as their discussions, following guidelines by Wang & Burris (1997). In order to achieve this, they developed different layouts by creating photo collages on PowerPoint presentations, printing them and stapling them on to small portable display boards and creating private YouTube videos with their photos. The photos used for these were photos that were representative for each sister of the top 5 descriptive categories that emerged after clustering and counting their photos.

Phase 6: Building upon a series of Photovoice stages described above, the sisters were encouraged to think about spaces for learning and alternative ways to promote their agenda,

which we then translated into projects in their local community for a week, in order to expose data to a greater audience and to encourage community dialogue. TD sisters held meetings to identify the key messages they wanted to share with the public inspired by their top 5 categories and determine the venue and duration of the community events. Sisters worked with the first author in order to recruit volunteers from the board of trustees from local and national parents associations, local schools and national local policy makers working together in order to deliver a week of community events and drawing the attention of the media as well (local TV interviews, newspaper articles etc.).

Phase 7: Sisters were thanked, and social time was facilitated in order to allow time for reflection on their involvement in this study. In addition, discussions regarding post-study action points were held.

Analysis

Each individual and group meeting was audio recorded on a small digital recorder and they were all transcribed verbatim in a Word document. The data set that sisters' analysed consisted of their photographs, the recorded narratives explaining the photographs, as well as visual narratives such as photo collages, PowerPoint presentations, digital photo albums and photos from all stages which were collected and discussed by the siblings themselves during group meetings.

In order to effectively organise and reduce the amount of data collected throughout, we encouraged sisters to create descriptive categories and case summaries of the narratives developed during the Phase 3. These categories where presented to their group in Phase 4 and were all together further codified. The photos and the words became intertwined in this study so that both formed an integral part of the analysis. Analysing the photos without reference to the story attached to each photo would be likely to detract from understanding

the participant's experience. This was a collaborative process led by siblings themselves. The first author and one sister facilitated the meetings and took notes on flipchart paper. These were discussed towards the end of each meeting and served as thinking points for sisters to further clarify their identified codes and key themes. After sisters identified and gave names to the meaning units, the first author facilitated sisters to put these in categories and to further organise their quotations around their themes. A separate academic researcher-driven interpretative analysis was also conducted alongside but that is not presented in this paper. During the write up period of this paper sisters were encouraged to make suggestions and the final content was shared with them for their approval. After a few minimal alterations suggested by the sisters, they agreed with the interpretations of their analysis presented by the academic researchers. In presenting quotes verbatim, minor hesitations, word repetitions and utterances have been mostly removed, as well as names of places and organisations that the siblings mentioned. All quotes used to form codes and thematic units were translated into English independently by the first author and a professional translator (Native Greek). Efforts were made to keep the text as close as possible to the original. In order to achieve that, a third independent translator undertook the translation of the quotes this time from English to Greek and then compared his product with the originally collected Greek verbatim quotations from the interviews. The latter helped us to ensure that the nuance of the siblings' words has not been altered or lost in translation.

Results

Sister-driven photo categories

Of the 220 photographs, 197 photographs were usable (89.54%). A photo was usable if the sisters identified the image (clear photo), remembered taking it, and did not change their mind about sharing it with the researcher while they were categorising the pictures. All

siblings also brought approximately 80 usable photos (36.36% of the total amount of photos presented to the researcher) that they had chosen from their family albums. The main categories and the percentages of photos relating to each category are presented in Figure 3.

Figure 3:

The TD sisters further analysed their results by grouping their photos to create key themes accompanied by sample key quotes and a representative photo for each theme. Each quote directly answered one of the SHOWeD questions described in Table 2. See Table 3 below for an overview of sister-driven key themes, photo sample and sample illustrative quotes which were also presented in their local community

Table 3 here

Each theme is illustrated below by verbatim extracts from interviews. In presenting the verbatim extracts, some minor changes have been made to improve readability. For instance, minor hesitations, word repetitions and utterances have been mostly removed. In addition, all identifying information has been removed, including names of places and organisations mentioned by the siblings.

Sleep, bath, lunch routines and homework

Nine out of eleven sisters brought a set of pictures that were related to sleep habits in the family, bedtime resistance and repeated night waking, while all of them provided plenty of narratives around poor sleep hygiene. The sisters report this issue as affecting their concentration during lessons, compromising their relationship with some members of school staff (due to repeated incidents of them missing morning classes or arriving late) and creating an overall feeling of constant tiredness. For instance, Sasa described a scenario similar to all nine sisters in this study who shared a bedrooms with their autistic brother or sister:

He will resist going to bed, he will flap his hands while I try to sleep or he will scream something aloud, like aka kak aka aka ka. He will wake up at least one time during the night, jump in my bed, bang his hands on the windows or run to my mum's bedroom. I took this photo at 4:00 in the morning. Here, he is already in my mum's bed, twisting around. Mum, most of the time, tries to take him to her bed so that he does not wake me up on school days.

Sisters also reported everyday difficulties due to the efforts of their parents to establish appropriate food and eating skills on their autistic child by forcing them to comply with parental rules. Sisters mention that their autistic siblings not only prefer very limited types of foods, but also eat these foods in ways that their parents do not approve of. The sisters very often state that they find most parental interventions during lunchtime upsetting, as '*mum and dad cannot accept that this is the way he eats*'. Anna went on to give an account of her brother's behaviour during lunchtime with reference to her parents' reactions and the feelings she experienced as a result of their attitude. She stated:

It's impossible to sit down together and eat like any other family. My brother has his own rituals with food. My mum forces him and she tries to teach him how to hold the fork. My brother likes to feel his food with his hands and his nose; next, he separates all the different food materials on his plate and then he grasps one or two pieces that he usually holds for hours and then maybe eats them at some point or throws them behind the kitchen counter or the sofa. Dad gets furious and blames mum for that habit. I am very upset every time my dad shouts at mum about my brother's behaviour. At the end of the day, he can't eat like us. I have accepted that. Why can't they do the same? I think my parents annoy me more than my brother on this one.

All sisters attend high school and report having lots of homework and studying to do after school. Nine out of eleven report being very motivated to get good grades and study at university. They all share scenarios in which their homework worksheets or laptops had been destroyed or they had to compromise and work to lower standards due to environmental distractions. As Jenny puts it: '*It is hard to do your homework in the evening when your brother creates madness all over the place...*'

Sisters reported that they often do not feel supported with their learning at home by their

parents. Also, their learning struggles may be underestimated as parents often compare them with their siblings. To their parents they are the '*shining stars of our family'*, '*very able to do anything*'. For instance, Annie explained how her learning difficulties were not noticed by her parents till the age of 12:

> Only last year, at the age of 12, did my parents realise that I might need educational assessment and support in school. In their mind, only my brother needed support as his difficulties are obvious and constant. My difficulties were nothing compared to his, so it took a while for my mum to find the time to sit down next to me and see how much I struggle with spelling and oral instructions. I finally got a dyslexia diagnosis.

Awareness is not enough. Acceptance is the key

This theme includes the narratives of the TD sisters on their shared experience of things that '*only happens to you when your brother has autism'*, or '*that's what happens when you grow up with a brother with autism'* and '*lack of awareness and acceptance can make it very difficult'*. This theme was clearly illustrated in two of the most common categories of photos: birthday parties and school life

All sisters chose to bring into the research photos of birthday parties from many years ago. All participant siblings reported that their families, nowadays, do not allow them to have a party at home. For Marianne, the last time she invited her classmates to her home was '*a nightmare*':

> We used to have big birthday parties at home when my brother was younger; we used to have fun… The last few years, I celebrate my birthday at school. We don't invite people at home anymore… Last time we had a party at home, my brother jumped into my birthday cake. Everybody was laughing until he started screaming and taking off his pants… My classmates were laughing at my brother, especially the boys. Some girls said they got scared.

The pictures were chosen as very significant moments in the life of the TD siblings, as they represented moments when they were very proud, embarrassed or scared of the reaction of others. Nine out of eleven sisters mainly commented on sensory discomfort or a socially

unexpected behaviour. Ellie remembered:

> At the beginning of the play, I think nobody could tell my brother had autism. It all started when my brother started smelling the armpits of one of my friends. At first my classmates started laughing. Then someone pushed my brother away. My brother started biting his t-shirt and moving his hands up and down shouting. It was very embarrassing. I did not know what to do. I wanted to protect my brother and I pushed away the guy who pushed him. Then all the parents started looking at me and my brother. I felt we did not belong there. At home, we would laugh with this behaviour or we would just calmly walk away from my brother to give him a sign that we don't like it. Why do people have to be so rough with him? Outside home, around my peers, my brother is just not normal in their eyes.

The sisters reported that they had noticed that the word autism is featuring more the news on the TV, radio shows and some events occasionally are dedicated to autism. Alex noted:

> There is some awareness in autism, but not in autistic people. A person with high needs like my brother is often characterised as a complex person by our friends, teachers and specialists in the TV. But there is nothing complex about him... his differences should be understood and accepted.

While discussing different events during which they felt uncomfortable to be '*the one with a different brother*', all sisters agreed that the issue was not the behaviour of their autistic brother. In Natasha's words:

> It is hard (…) what to do when this happens? Explain to people what is going on? Accommodate the need, her need? as most of the times such a behaviour means she wants something and she has no way to explain to us, explain to others? Apologise for her behaviour? Tell them that you wish they were just more understanding and not making this a big deal? Get angry because they should just accept my sister how she is?

The sisters very often state that they find most maternal interventions '*unnecessary*' and '*putting pressure on my brother to change*'; however, they recognise that mothers are also always there to help with everything. Anna gave an account of how much she admires her mother, as she will stand up for her brother in public. She stated:

> In my eyes my mum is something of a hero. She has to deal with so much

indifference and obstacles every day around the community with my brother. My mum has taught me how to deal with my brother's tantrums, how to use photos to communicate and how to step back when things get too hard. My mum will advocate for my brother when using public transport or public toilets. My mum showed me that it is possible to let people know what my brother needs and to fight to get it if necessary.

Amelia added that is the community that needs to consider changing, not her brother:

How can someone say my needs are ok to deal with, but our siblings' needs are not? Why my brother has to be the 'other', getting all the weird looks and not having a chance to have fun and be himself? It is true that things can be difficult with my brother when his needs are not met by his environment. Little things such as accommodations in order not to wait in long queues, having a quiet space in the café, someone to help him cross the streets can make a huge difference in his quality of life. I don't want my brother to change; I need my community to change.

Alex, similarly to all sisters who participated in this study, dreams of a more inclusive community.

I dream of a community that will allow my brother to be part of everyday ordinary things, without people getting angry by his behaviour (…) People like my brother need more opportunities to participate in the community in ways that makes them happy and comfortable

Love is in the air

This theme includes the narratives of sisters regarding their positive feelings towards their autistic siblings and their extended thoughts on difference, acceptance and commitment to the positive side of things, including shared time, acceptance and the fact that they share '*feelings of unconditional love*' towards their autistic siblings. Eliza explained:

The world autism came in my life few years after I met my sister… Autism is something I can't think as a separate thing. I can't think of my sister being something else, her autistic self is her normal self for me. This is how I met her and this is how I learned to love her.

All sisters spoke about the different ways they view their autistic siblings' sensory,

communication and thinking differences as part of their autistic identity. Sisters mentioned

different activities that they enjoy sharing. Natasha noted:

> My sister is the only person that I can spent silent time with, she does not talk to me
> and she does not like me talking too much either. Sometimes we share my bed and
> there is so much silence and so much love in the air even if we do nothing
> particularly fun. I think there is something really cool about it as after few minutes
> of silence we will burst into laughs and might start singing, which is also nice but
> these moments that we are just sitting silent she [meaning the sister] her eyes speak
> volumes to me.

They perceived their siblings as different, but not in a negative way. They seem to feel that

autism is an integral part of the brother or sister they '*love each other just like siblings do*'.

Katerina explained:

> I try to mirror his actions sometimes, just in case I feel how he feels, just in case I
> understand what's in his mind. It takes a lot of patience to understand someone who
> is part of you but so different. We have the same blood, we like the same pizza
> toppings, but we can't speak to each other in the same language. I simply like him
> for what he can do and love him because he is my brother. I don't want him to
> change. Autism is part of who he is. This is how he was born like that. It is integral
> part of him; you cannot take it away.

Sisters very often described their siblings as '*interesting*', '*sensitive*' and '*honest*'. All sisters

declared that autism becomes a '*struggle*', '*complication*' or '*difficult to deal with*' due to

others' reactions.

Autistic siblings' needs often remain unmet and sisters feel that their role is to advocate on

behalf of their siblings until '*everybody understands*' because '*what else can you do when a*

member of your family is not loved by others for who he is?'

Ten out of eleven sisters confess that they put considerable effort into making sense of their

siblings' communication and sensory patterns through shared time together. This can be '*both*

an exhausting experience and a learning opportunity'. Seven sisters mentioned that they are

committed to finding ways to advocate for their siblings or people who are different in any way because '*being able to love others without rules about how they look or what they do is a big thing*' and '*love is everything*'. Tina gave an example:

> It has made me think a lot about people who look different, talk different, sound different. We live in world with too much hate and the first to experience hate are those who are different. I have lived all my life with someone who is different, and I feel how people might feel fear or hate for anything that does not seem normal to them. My sister has taught me to tolerate things and to experience difference as normalcy. I wish, when I grow older, to find ways to advocate for these people, as they need people who understand them to stand up for them. We should not expect from a kid to be less autistic in order to be included in ordinary life. We should make ordinary life more accessible for autistic kids (…) I love my sister and I want this world to love her so that she can trust people and live her life happy.

Sisters just want to have fun

This theme includes the narratives of sisters on their perceived strengths and resources which cultivate positive feelings or in their words what '*fun times*' during which '*you are yourself, just you, not a child or a sibling just you enjoying*'. Sisters mentioned that having fun '*is not just happening*' and '*is something that needs to be well planned sometimes many weeks ahead*'. Ellie explained:

> Being a sister of an autistic brother means I have less time for myself. Balancing different caring tasks, schoolwork and personal time is always an issue. I want to have fun. I try hard to make it happen (…) not giving up on what you want is important.

The most important categories of photographs related to this theme, as ranked by the sisters, included their closeness with their cousins and the areas in which they feel talented or prefer to spend their leisure time.

Seven out of eleven brought in photos of themselves with their mothers. Sisters report warm and close relationships with their mothers despite often having disagreements with them. Their mothers were reported to be the main sources of information for sisters and the ones

who are more available to discuss things or '*use some humour when things get totally wrong and help us all to get over an argument*'.

Six sisters suggested that cousins were acting as '*best friends*', '*social supporters*' and '*good company*'. Sisters brought photos with their cousins which mostly represented fun and comforting activities. Cousins of same gender were described as '*good listeners*', '*a person whom I can trust because she knows my history and present*', '*like a second sister to me*'. Marianne explained how her cousin's visits feel more comfortable for all family members:

> My cousin is one of the very few people of my age who can visit without us panicking. We are all comfortable with her as she knows us, she knows about autism and she is comfortable around my brother. That saves me and my parents from feeling worried or awkward having a visitor who does not understand my brother… You know, my brother can also run free and stim without having critical eyes on him. With my classmates I would feel worried to tidy up, to make sure my brother does not show up a lot in the living room… it's just harder.

All sisters agreed that not being '*worried about what will happen when someone visits for a play date or a sleep over and a movi*e' is a vital condition for sisters to start relaxing in order to have some '*much needed fun with the someone who understands me*'.

Sisters also named a number of different group or solitary activities that they enjoy such as '*dancing lessons*', '*martial arts*', '*taking care of pets*', '*drawing alone in my room*' and '*playing outdoors after school*'.

Sensory journeys - Finding out what works together

This section includes sisters' narratives which provide evidence of how parents and sisters collaborate and communicate in reciprocal ways in order to create flexible environments to accommodate siblings' needs at home and support each other by providing information and sharing observations. Tina, Sasa and Jenny respectively reported:

> It is all sensory. She [meaning the autistic sister] pays so much attention to all the things in her environment. She will spend most of her time doing these things with her head, her hands, smelling and touching or move her body in all unusual

ways…we [sister and parents] we observe her and that helps us to understand what works

We know how to make it work, my dad will try to be quiet, I will lower the lights or the noise in his room, my mum knows his favourite foods…. These little things help her a lot to be regulated, to be in good form and to stay in a good mood

I often share information about my observations with my parents and vice versa. This way we can stay more tuned to her sensory needs- which change from time to time

Today my mum - tomorrow who?

Sisters described having witnessed the struggle their parents face daily in order to get social support. They also report to have seen in the news increasing incidents against 'the other' (immigrant, mentally vulnerable, disabled) and heard about increased reported incidents of chemical and body restraint practices against autistic teens and young adults in private and public institutional care sectors. Sisters wonder what '*will it be like*' when her mother cannot '*battle anymore in order to give him [meaning her brother] access to essential services*'. Alex reported:

> My mother is my brothers' carer; I help my mother with everyday things but in reality, my mum is the main person who is around my brother 24 hours. I keep wondering what will happen when my brother becomes an adult? Who is it going to be the key person in his life?

All sisters reported being worried about what the future holds. In their discussions they mentioned that '*it should be easier but its not*' and shared common experiences of '*wondering what will happen in the future*'. Amelia explained:

> I often think what will happen in the future if I leave the house and go to university or decide to have my own family. Who is going to help my mum if I am not there? And what will happen if one day my mum is not able to offer support to him?

Ann added the following:

> I have realised that my sister will have high needs no matter how much progress she is making over the years. In our city there are no community centres for autistic

adults. There is no space or specialist to my knowledge who could help my sister once she becomes an adult. So yes (…) lots of questions about the future which remain unanswered

The accounts of sisters also revealed that the support programmes that their families were involved during the time of the analysis of the data often targeted therapy outcomes for their autistic sibling, and individual sisters were rarely consulted about their ideas, needs or what does not work for them. Jenny noted:

I have been excluded by all professionals who have worked with my family, no one ever asked me about my brother, my family or me. I have no idea what is it like to speak with services and to ask for help. My mother is skilfully managing all these. I wonder what will happen when my mum gets old and tired. Where do I start with all these? Who will help me?

Sister-driven community events

The momentum created at an individual level and during Photovoice groups continued at community level, and involved researchers, local community and key policy makers.

The TD sisters led a multimedia presentation of their experiences, needs and priorities in the form of artistic videos, talks and a Photovoice exhibition that took place for a week at their local community centre. Local schools, policy makers and healthcare professionals attended (see Figure 4).

Figure 4

Panel discussions raised questions such as "*What do teachers need to know about the siblings*?", "*Can we democratise family research and family intervention in families with complex needs*?", and "*What do siblings wish you to know*?". The event was covered by a number of local TV and social media. Sisters gave TV interviews and joined panels with representatives from local authorities, Trustees from local autism charities and national policy makers.

Sisters' and academics' partnership and further action plan

In a post study group, sisters and researchers developed together action items based on sisters' expressed needs and perspectives. The items of this plan, which are summed up in Table 4, were shared with local press and trustees of local autism charities at a national level (through Photovoice Exhibitions across Greece) and at an international level with university researchers and siblings participating in the Siblings' Research Advisory Group (SRAG) in the UK.

Table 4: Post study action plan co-established with sisters

Discussion

Siblings' experiences can be often difficult to fully capture using traditional methods such as word alone interviews. Many everyday activities are likely to be left unexamined and unquestioned by researchers. Despite the fact that involving participants in all stages of research has the potential to make research more responsive to existing needs and to enhance a community's ability to address important issues experienced by siblings, it has been largely ignored in autism siblings' research.

In the present study, sisters were invited to capture images that triggered thoughts around salient experiences, strengths and concerns that were then discussed in interviews and focus groups. The current study is the first one to actively involve siblings in all steps of the research: i) collecting photo data; ii) determining the content of the data and categorising it; and iii) analysing and interpreting the data. It consisted of their observations, experiences and reflections on the sibling experience.

The photographs, narratives and descriptive themes captured and highlighted the feelings, needs and thoughts that these girls may experience, not only in the family, but also as students and young females in the community. All sisters explained how they wanted to

remain as close to their sibling as possible, but also be independent and social outside of the family. Sisters' accounts implied that there is currently a lack of available support suitable to their needs in a number of areas such as accessing information about their siblings' conditions and planning for adult life. The conversations in the Photovoice groups recognised that teenage sisters are excluded from proactive clinical planning and services and the only source of support and information is the mother. This finding is similar to Greek parents' views of raising an autistic child in Greece (Tsibidaki & Tsamparli, 2007; Papageorgiou & Kalyva, 2010). The current study provided us with rich descriptions of sisters' subjective experiences of siblinghood in their everyday life (e.g. birthday parties, school assemblies, eating routines, sleep issues etc.). 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. Also, new themes such as the impact on education emerged. While further research is needed to confirm and expand upon the insight obtained in relation to school experiences, the findings here build foundations in understanding the direct and indirect effects of having an autistic sibling on the school experiences of their TD siblings.

While siblings of disabled people are often strong advocates for and with their disabled brothers and sisters (Burke, Arnold & Owen, 2015), little is known in which ways future personal choices may be affected. The sisters in this study expressed strong advocacy feelings towards a more inclusive society and raised questions around the future, noticing that within their local communities, there is no specialised support available for autistic adults.

Sisters' accounts revealed that positive and frequent interactions were occurring between the sisters and their mothers, but less so between the sisters and members of their extended family or peers; where at times they felt uncomfortable and as being "different". This is very similar to the findings of Petalas, Hastings, Nash and Duff (2013) in their study, in which

siblings made social comparisons and complained about their peers' reactions. Sisters reported that the reactions of peers (e.g. through photos of school assemblies or birthday parties) as well as fathers/extended family members were perceived as non-positive at times. The latter might explain why the sisters preferred to present photos of their mothers as an exclusive category. Both the mothers and the sisters were reported to play an active role in influencing each other and sharing caretaking responsibilities, while creating intimate moments together. This finding supports recent work by Chan and Goh (2014) with families in Singapore, which reports that the relationship between mothers and their TD siblings is generally good.

Strengths and Limitations of the current study

The current study used a novel multi-step modified Photovoice methodology. This is the first study to use a Photovoice methodology modified by adolescent sisters themselves in order to empower sisters to act as co-researchers sharing their valuable knowledge by using photographs and narratives in their preferred ways. This approach introduces some important participatory elements throughout the different stages as outlined earlier in this paper, however, this study can only be considered as partially participatory as participant sisters were not involved in the choice of the topic and also, the Discussion section of this paper section presented in this paper was largely driven by the interpretations of the academic authors.

Additionally, our study had a strong community focus. Weiner and McDonald (2013) describe community-based methods as a collaborative process between community-based organisations and academic investigators. This is the first siblings' study in the field rooted in positive youth empowerment aiming to shed light on the ways sisters interpret their social, structural, and environmental influences through active involvement of community members and organizational representatives (board of trustees, autism charity professionals and local

schools) in order to engage the community and initiate social action by promoting awareness and stimulating public dialogue around sisters' experiences and needs.

Finally, it has been noted that all published sibling research to date has a narrow focus on simply engaging siblings in research and documenting their lived experiences. This study aimed to involve sisters in the dissemination of their messages in accessible ways that can engender changes in both policy and everyday practice. In the last stage of this study, sisters were encouraged to share the material that was created during the Photovoice stages with local policy makers, teachers, school students and therapy teams and to discuss post-study plans with the researcher. We argue that when knowledge about the lived experience is drawn directly from the perspective of the actual people (sisters) involved in the phenomenon (siblinghood and autism) and shared with their local community we maximise chances for a more appropriate, responsive and need-fulfilling strategy of proactive support to be initiated in areas defined by sisters themselves. Finally, community participation in our research strengthens the links between siblings, their families and local decision makers.

Implications for research and practice
The methods applied in the current study may be of considerable significance for the formative stages of further research studies. Photovoice methods have been adapted in a novel way with, rather on or for, sisters. The approach utilised in this study contributes to the growing methodological innovations and developments in siblings and family research by enabling sisters to analyse, structure and present the visual and narrative data ensuring their voice is included across all stages of research. The participatory elements of this study are in line with the broader notion of service-user empowerment in healthcare and increased participatory citizenship for individuals with disability and their families. A scientific attitude which underlines the importance of empowerment through understanding the human

experience is in line with recent and current calls in mental health (Department of Health, 2012; House of Commons, 2018) as a way to address current professional and research gaps in the field.

The findings of the current study point to several positive experiences, especially during siblings' shared time activities. This message is important for parents, siblings and people with autism themselves. It can also inform the current beliefs that underlie some autism intervention practices, as it moves away from the notion of the pathologisation of autistic family members where they are always seen as the 'problem' in the family. Future research should examine more closely any positive effects or critical events for the development of such warm feelings for their sibling.

Practical issues such as the legal role of adult siblings, and the support available to aging siblings caring for an adult with learning disability should be further explored. Finally, we recommended in the future that such participatory research efforts include autistic siblings' experiences of siblinghood and opportunities for wellbeing. The exclusion of the autistic voice in siblings' research reinforces the devaluation of their experiences, perspectives and needs. Researching with typically developing and autistic siblings utilising participatory visual designs may positively change the power dynamics in autism research and help us widen our perspectives on siblings' experiences and needs.

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In their own words, in their own photos: Adolescent females' siblinghood experiences, needs and perspectives growing up with a preverbal autistic brother or sister.

Abstract

Thus far very little research has focused on siblings in early adolescent years growing up with an autistic sibling. Adopting a community-based participatory research (CBPR) approach, 11 typically developing sisters actively collaborated in the study to collect and analyse data as well as disseminate their experiences, needs and perspectives in their local communities. This is the first study to use a modified Photovoice methodology which provided typically developing sisters an active participatory role. The results highlighted the feelings, needs and thoughts the sisters expressed in their role as siblings, friends, but also as students and citizens with a passion for advocacy, and limited support in the community due to unhelpful attitudes of members of their community towards autism.

The findings indicated that the current method used can successfully co-generate research findings with family members by ensuring pathways for engaging local community. This is crucial in shifting the balance between vulnerability and resilience in families raising an autistic child. Furthermore, when knowledge about the lived experience is drawn directly from the perspective of the actual people (siblings) involved in the phenomenon (siblinghood and autism), a more appropriate, responsive and need-fulfilling strategy of supportive and proactive support systems can be initiated.

Keywords: siblings, autism, family mental health, community-based participatory research, Photovoice

What this paper adds

This is the first siblings' study in the field rooted in positive youth empowerment / community based frameworks, adopting a community based approach in the study of siblings' experiences in the field of autism family research. Sisters, as co-researchers, collaborated with academics across all stages of research. This enabled sisters to share their views, representations and perceptions of growing up with an autistic brother or sister in the community.

Co -produced by sisters and academics, the current study looks at the ways sisters may be involved in sibling research to describe their experiences, priorities and needs as well as the ways we may involve them in educating their local communities around disability issues, promote acceptance and challenge communities' sense of 'normalcy'. This study shows that a participatory research framework is possible and essential in siblings' research so that the sibling research agenda can reflect the priorities and needs of the siblings themselves.

Highlights

There is a growing number of research examining siblings' experiences where one siblings is autistic. Most of this research has used word-alone interviews to examine the impact of autism in the family. The methods applied in the current study may be of considerable significance for the formative stages of further research studies.

The findings of the current study point to several positive experiences, especially during siblings' shared time activities. This message is important for parents, siblings and people with autism themselves.

This study may help researchers and professionals enhance their understanding of family experiences in families raising an autistic child with additional learning disabilities beyond a deficit perspective by noting the opportunities for wellbeing and the struggles in the life of siblings, which often are the result of parental and societal reactions to their autistic siblings.

Table

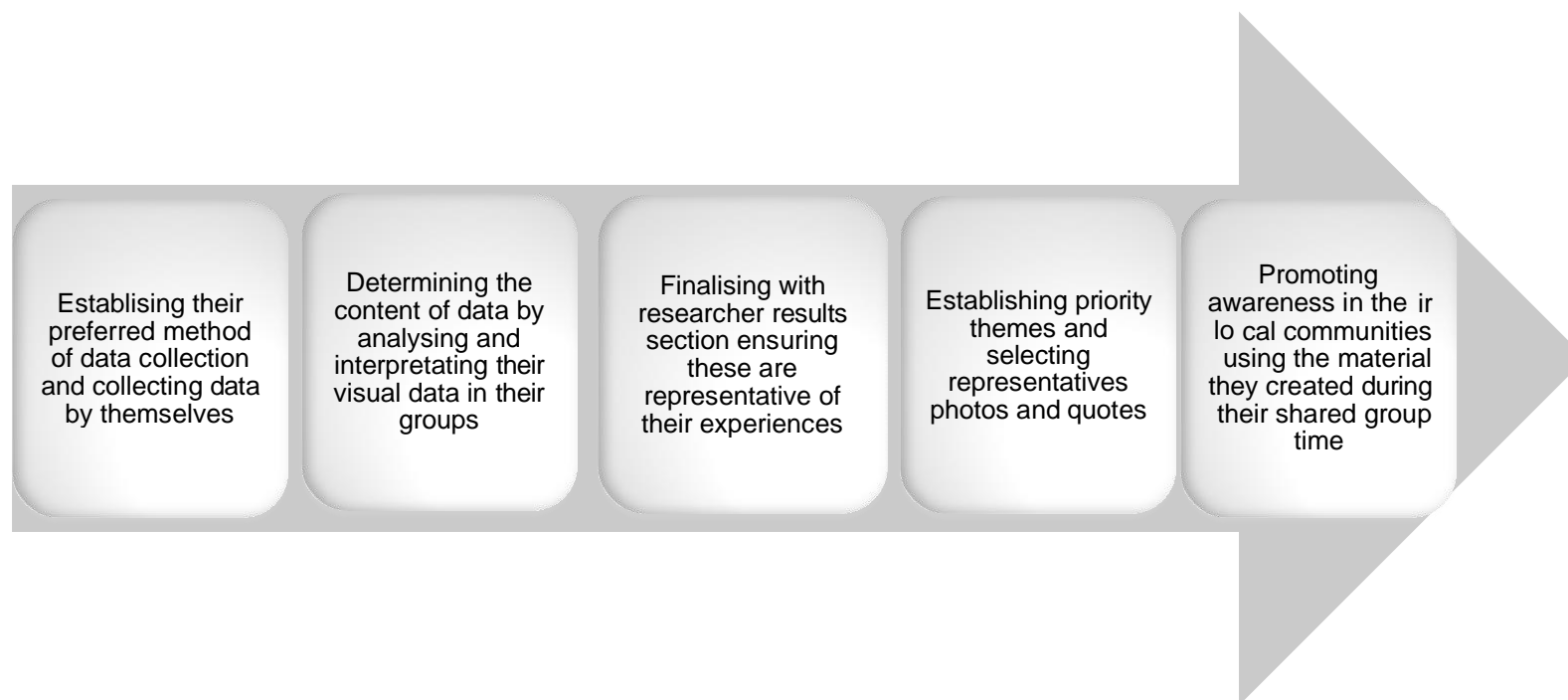Figure 1: Procedures of sisters' engagement in current study

| Establising their preferred method of data collection and collecting data by themselves | Determining the content of data by analysing and interpretating their visual data in their groups | Finalising with researcher results section ensuring these are representative of their experiences | Establishing priority themes and selecting representatives photos and quotes | Promoting awareness in the ir lo cal communities using the material they created during their shared group time |

Figure 2: Adapted Photovoice stages

Phase 1	Phase 2	Phase 3	Phase 4	Phase 5	Phase 6	Phase 7
4 weeks 4 meetings	3 weeks Daily	12 weeks 22 interviews	16 weeks 8 meetings	3 weeks 3 meetings	2 weeks photo exhibition; 2 talks; 1 month in local news	Debriefing
Conceptualising the topic and establishing research question Training on ethics of photography Recruiting policy makers Defining study objectives and data collection procedures Descriptive analysis data training	Photo taking and writing narrative collection	Narrating photos through individual face-to-face photo elicitation interviews	Group discussion based on the photos using SHOWeD protocol Selecting, contextualising and codifying photos and personal narratives	Lay down sister-driven themes for exhibition Prepare multimedia stories for audience	Community exhibition Talks in TV news and local newspapers	Closing celebration Debriefing/Evaluating Study Defining post study action plan items

Figure 3: Sisters'-driven photo descriptive categories and percentages

Category	Percentage
SLEEP/LUNCH/BATH ROUTINES	25%
FAMILY MEMBERS; AUTISTIC SIBLINGS,...	22.4%
SENSORY BEHAVIOURS	4%
HOBBIES	9.4%
SCHOOL LIFE	10%
SIBLINGS' SHARED TIME	13%
BIRTHDAY PARTIES	16%

Figure 4: Siblings raising awareness and acceptance of autism in their local community

Table 1: SHoWED protocol

S   What do you See happening here? (Describe what the eye sees)

H   What is actually Happening here? (What is the unseen story behind the picture? What does the heart see?)

O   How does this relate to Our lives?

W   Why does the problem/strength exist?

E   How could this photo Educate others about the life of sisters?

D   What can we Do about it? (What can researcher/parents/teachers/policy makers do in order to improve family life in your community?)

Table 2: Siblings 'demographic background

TD sisters' pseudonyms	TD sisters' age in years	Autistic sibling's gender	Autistic sibling's age years	Parent Marital status	Family Socioeconomic status
Tina	13	Female	12	Married	Lower
Amelia	13	Male	12	Married	Lower
Marianne	14	Male	10	Married	Middle
Eliza	13	Male	13	Married	Middle
Jenny	13	Male	14	Married	Lower
Ellie	14	Male	11	Divorced	Lower
Natasha	13	Male	11	Divorced	Lower
Katerina	14	Male	11	Married	Middle
Alex	14	Female	12	Married	Lower
Sasa	14	Male	12	Married	Middle
Anne	14	Male	11	Married	Lower

Table 3: An overview of sister driven key themes, photo sample and sample illustrative quotes which were also presented in their local community

Key themes	Photo sample	Illustrative quotes
Sleep, bath, lunch routines, homework		"You always sleep with one eye open, in case he has an accident, or something happens." "In many occasions during the day I feel that I have to help, and it is part of our family routine…. with things like lunch or dinner or making sure he is safe in the toilet." "There is this love duty. And a necessity too. If I don't help, mum or dad will have an argument with him for not eating or with me for not helping." "Is hard to ask for help as mum is always busy and in fact, I have to give help."
Awareness is not enough Acceptance is the key		"I hear the word autism in the tv and in the news nowadays. Yet I am not sure people understand my brother as an autistic person." "A person with high needs like my brother is often characterised as a complex person by our friends, teachers and specialists in the TV. But there is nothing complex about him... his differences should be understood and accepted."

Love is in the air		"The world autism came in my life few years after I met my sister… Autism is something I can't think as a separate thing. I can't think of my sister being something else, her autistic self is her normal self for me. This is how I met her and this is how I learned to love her." "I love him and I know he loves me too. It is pure siblings' love and the condition cannot compromise my love." "Sometimes we share my bed and there is so much silence and so much love in the air even if we do nothing particularly fun. "
Sisters want to have fun		"Being a sister of an autistic brother means I have less time for myself. Balancing different caring tasks, schoolwork and personal time is always an issue. I want to have fun." "There are many things that make me feel good, having social time and spending time with peers or taking part in after school art clubs is fun." "I need to remind my parents that I need time to be alone or to be with friends outside home. I have to claim my time and often negotiate with my mum."
Sensory journey Finding out what works together		"We know how to make it work, my dad will try to be quiet, I will lower the lights or the noise in his room, my mum knows his favourite foods…. These little things help her a lot to be regulated, to be in good form and to stay in a good mood." "I often share information about my observations with my parents and vice versa. This way we can stay more tuned to her sensory needs- which change from time to time. "

Today my mum, tomorrow who?		"I often thing what will happen in the future if I leave the house and go to university or decide to have my own family. Who is going to help my mum if I am not there? And what will happen if one day my mum is not able to offer support to him? " "I have been excluded by all professionals who have worked with my family, no one ever asked me about my brother, my family or me. I have no idea what is it like to speak with services and to ask for help. My mother is skilfully managing all these. I wonder what will happen when my mum gets old and tired. Where do I start with all these? Who will help me?"

Table 4: Post study action plan co-established with sisters

Identified Need	Action Item
Promoting acceptance/Sharing results with local community	Sharing results with local mainstream schools through Photovoice exhibitions
Sharing findings with autism researchers and professionals	Distribution of study report with links from media who covered the event Posting study summary/key points on non- profit websites. Write up paper for a peer-reviewed journal
Raising awareness at a national level of sisters' experiences, needs, priorities	Produce policy report with results of study for healthcare family practitioners and families Use study data to increase funding via additional grants for non-profit autism sectors in 3 areas across XXX Incorporate a maximum of 10 photos and 1 multimedia video story approved by sisters along with unlimited textual narratives when presenting in international conferences and research meetings
Validate and refine sisters' themes and needs across different cultures by applying same methods in international family research	Reinforce community based participatory with all family members including autistic siblings