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'It's different, but it's the same': Perspectives of young adults with siblings with intellectual disabilities in residential care

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Keywords:

Accessible summary

- Siblings often play important roles in the lives of people with intellectual disabilities

- This study suggests that young adults who have siblings in residential care can feel isolated in their experience

- Adolescence appears to be a turning point and a time when siblings become aware of future caretaking responsibilities

- There is a need for support for siblings of children and adults with intellectual disabilities who live in residential care

Abstract

Background: Siblings often play significant roles in the lives of people with intellectual disabilities. This study aims to give voice to young adults whose siblings have an intellectual disability and are in residential care.

Materials and Methods: Six participants were interviewed, with Interpretative Phenomenological Analysis methodology employed.

***Results*:** Emergent themes included family and sibling relationships and concerns for the future. However, ambivalence, in terms of conflicting feelings within participants themselves, was striking. Dissonances within narratives included identifying as 'one family' whilst living apart, experiencing guilt while being supportive of the residential placement, and emphasising the normality of the sibling experience whilst also feeling different and isolated.

Conclusion: These findings reflect the particular complexity of sibling relationships when the person with an intellectual disability lives in residential care. There is a need to understand more about the perspectives of siblings, and the influence that residential care may have upon these.

Introduction

Many families of children with intellectual disabilities report positive experiences, such as a gaining alternative perspectives and increased opportunities for learning (Davys 2013; Pelchat *et al.* 2009). However, the support needs of children with intellectual disabilities can place a significant burden upon close family members (Davys *et al.* 2015; Emerson *et al.* 2010).

Even in families where parents are the primary caregivers, siblings often take on secondary roles, with responsibility increasing during adulthood (Rawson 2009). This appears to be true across cultures (Derivishaliaje & Murati 2014; Ying Li 2005). Although much of the early research pathologised the sibling experience (Lavigne &

Ryan 1979; Martino *et al.* 1974), studies employing qualitative, phenomenological designs suggest that having a sibling with an intellectual disability can be a positive or benign influence (Davys *et al.* 2015; Heller & Arnold 2010; Rossiter & Sharpe 2001).

As the availability of funded community support diminishes, and the life expectancy for people with intellectual disabilities increases (Hallam *et al.* 2002; WHO 2000), the role of siblings will become increasingly relevant (Burke *et al.* 2012; Davys 2013). Given this, it is surprising that our knowledge of the perspectives of those who may provide the closest and most continuous relationships for individuals across their life is relatively limited (Arnold *et al.* 2012; Whiteman *et al.* 2011). Indeed, a number of studies have indicated that siblings feel `invisible´ to policy makers, service providers and society in general (Arnold *et al.* 2012; Rawson 2009).

Although there is a general trend away from residential care for children with intellectual disabilities, there are some individuals, with particular needs, where this is considered the most appropriate option for care (Rawson 2009). Thus, when children are being looked after away from the family home, because of their more complex needs, support and dependency on others is likely to be greater across the lifespan. This is likely to lead to a greater need for close involvement of family members, particularly siblings, as the individual reaches adulthood and may return from residential care to a community setting.

Siblings play varying roles and face multiple issues at different life phases, thus there appears to be a need to understand the changing nature of the relationship across the

life course (Burke 2001; Davys *et al.* 2015; Greenberg *et al.* 1999). The time around adolescence and young adulthood may be a particularly crucial period for both the individual and their sibling, as it may, arguably, set the scene for the developing relationship as siblings age. Furthermore, the complexity of this relationship may be magnified when the sibling is placed in residential care. Existing studies have tended to focus upon the interactions of siblings who live together (Harland & Cuskelly 2000; Moyson & Roeyers 2012). Thus, the perspectives of siblings where one is placed in a residential setting, presents a significant gap in the literature (Eisenberg & Baker 1998).

The present study aims to build on the existing knowledge base about siblings of children with intellectual disabilities. It will attempt to understand the views and experiences of young adults who have a sibling who is placed in a residential school.

Methodology

The current research is concerned with exploring the perspectives of young adults whose siblings are placed in a residential school. Due to the complexities of these experiences, this study adopts an IPA approach. Analysis will attempt to uncover the key themes and meanings that emerge from interviews. IPA appears appropriate to this specific research question, in that it engages in interpretative methodology to access an individual's cognitive inner world, is able to capture convergence and divergence of the lived experiences and furthermore acknowledges the subjective, unique form of experience of one person in a given context in a given point in time (Smith *et al.* 2009; Wagstaff 2014). IPA acknowledges that the researcher's involvement with the participant's story has an interpretative element (Murray &

Holmes 2014). Therefore reflective diaries, supervision and reflection with a colleague were used to increase the researcher's awareness of her own influences and pre-conceived assumptions, in order to increase the credibility of the analysis.

Participants

Purposive sampling was utilised, with six participants recruited for the study. All were siblings of pupils of the same residential school for children and young adults with intellectual disabilities. The levels of learning disability of siblings varied from severe to profound, with siblings also having a number of additional diagnoses that included autism, specific genetic syndromes and additional physical health needs. All siblings were resident in the school for a minimum of 42 weeks-per-year.   Contact arrangements varied between families, ranging from home visits at weekends or holidays, to contact only through visits within the school. Inclusion criteria for participants were an age of 16 to 25, although actual ages fell within a narrower age band of 16 to 22 years. Although there was a degree of homogeneity between participants, each participant had unique characteristics of his or her own. An overview of participants can be found in Table 1.

[Table 1 here]

Ethics

Ethical approval was granted by the University of Edinburgh and the residential school's ethics committees. All participants gave informed consent and were made aware that they were free to cease participation at any time. Individuals and organizations were anonymised in the process of transcription. Limits of

confidentiality included situations of risk toward either children or vulnerable adults, including issues of poor care standard and conduct from school staff.

Interviews

Semi-structured interviews were used, with open-ended questions that allowed space for individuals to express views, feelings and relate experiences that may have been unique to them. Questions were structured around past, present and future experiences on (1) nature of their relationship with their sibling, (2) roles and involvement and (3) wishes, hopes and concerns for the future. This structure was felt to address the areas of interest from the research questions, mirroring recent similar studies in the literature, but also allowing participants the opportunity to express their own views. A copy of the interview schedule is available from the author.

Data analysis

The analysis was carried out in accordance with Smith's guide (Smith *et al.* 1999) to using IPA. The analysis was carried out case-by-case, moving from the particular towards more general emerging themes. In the end a consolidated master list of themes for the whole group was developed. Dedoose (2013), qualitative research software, was used to support the process of identifying themes and to assure that those were grounded in the participant's narrative. The anonymised transcripts and the line-by-line analysis of emerging themes was peer reviewed by a postgraduate researcher with experience in qualitative methodologies. Furthermore, transcripts and the list of superordinate and subordinate themes were reviewed by the co-author and both researchers engaged in frequent discussions about the identified themes. The researcher engaged in a reflective process throughout the research.

Researcher

The researcher completed this study as part of a postgraduate qualification. She worked within residential care for eight years previous to the research undertaken. In this time she had been involved with the residential school through which participant recruitment took place. However, she had no involvement with the participants and had finished her employment with the school when the research was undertaken. Participants were made aware that the researcher had previously been employed by the school, but that this was no longer the case. Inevitably, the researcher's background impacted on the assumptions she had going into the interviews. Preconceived ideas about residential placements leading to higher degrees of separation in the sibling relationship were noted down and a reflective diary was employed to be conscious of possible influences of those assumptions on the interviews.

Themes

Super- and sub-ordinate themes that emerged from the data are described in the following section. Table 2 (below) gives an overview of the super- and sub-ordinate themes, and the variety of variables, that were present in the interviews. An overarching theme of Ambivalence was expressed throughout the interviews and across topics.

 [Table 2 here]

Family Relationships

The way participants spoke showed that their experience was strongly embedded within the family culture. For most participants, their sibling was constantly referred to through conversations, sharing memories and contact with the residential placement.

I think about X, we always talk about her and stuff (…) like no she is always here, like we never not think about her when she is not here (Kelly)

As can be seen in the excerpt above, participants frequently switched between first-person singular (e.g. I think) and first-person plural (e.g. we do). This can be seen as evidence of the central role the whole family system played in the experience. Mothers seemed to be central in facilitating a sense of belonging and involvement of siblings. Taking on support roles to assist mothers was described as natural while also causing participants stress and feelings of frustration. Supporting mothers from early ages led some of the participants to experience reversed roles such as "The oldest one" or a "3rd parenting" role.

I quite quickly assumed a natural older brother role in the, or almost like, a third parenting role borderline, because he doesn't, he needs the, his constant care and attention. If my parents have got their backs turned it is to me (James)

Dealing with behaviour that challenges and supporting siblings with intimate care were associated with higher levels of stress compared to remaining vigilant for their

sibling's safety around the house, or supporting in daily activities such as meal preparation. The complexity of siblings' needs appeared to be central in the family's decision to seek a residential placement. Since the residential placement had been found, participants described feeling less burdened. Negative aspects of the residential placement connected to physical separation, feeling guilty and missing their sibling. However, none of the participants questioned this decision and all admitted feeling less worried or guilty as they could see their sibling was happy and making progress; this seemed to play an important role for participants to come to terms with the placement decision.

But I knew it was the best for her when she went there even you could see after a month like her language had improved, like everything improved and that was really, that made me happy (Clara)

Despite the physical separation, the placement also seemed to have a positive effect on the sibling relationship. Seeing their sibling at visits applying themselves at activities and interacting with peers seemed to help participants to view their sibling as a person with strengths, interests and social networks.

Yes it is nice to see what she gets up to. Like what her personality is like as well at school and yeah it is really good because she gets to do a lot of activities that she wouldn't do here (...) She can go swimming, horse riding. She is like, she can bake and paint and felt and stuff like that, so (Lisa)

Having a sibling with disability seemed to be a strong and central experience of the

family and the family's norm, although participants simultaneously also realised the uniqueness of their situation and how it made them, their sibling and their family different. Participants repeatedly used the word 'normal' and stressed how neither their sibling nor their relationship was any different to that of other families. At times, participants spoke of the difference and normality of the experience within one sentence.

Even 'cause we have always been taught like not to treat her differently because she is just one of us even though she is not really one of us cause she has got a disability but she is, she is just one of us (Kelly)

It appears that participants struggled with the concept of being different which seemed connected to feeling misunderstood by others outside the family. Describing their experience as normal seemed to express a wish for not being different. In this sense, difference seemed to be connected with negative prominence. Participants described feeling isolated within their experience and unable to talk to others outside the family.

It's hard as well because when you are trying to explain to friends they don't really understand (Susie)

Sibling relationship

In addition to the role of the family, participants gave a more personal account of their experience as a sibling. All expressed feeling very close while also describing that they struggled at times. However, participants were able to see their experience as a

unique possibility to learn. Positive aspects included being more mature, patient and understanding. Three participants highlighted having a sibling with intellectual disability as a life changing and powerful experience, which they would not want to have had any differently.

Even though it is difficult and I have struggled over the years but she is like my favourite sister so yeah (laughs) yeah she is my favourite person and yeah I wouldn't change her (Lisa)

All participants stressed that they felt close to their sibling, but expressed that the disability and difference in communication or perception of their brother or sister led to a sense of separation.

So it is really hard for me to see her getting frustrated cause I am not understanding, if you know what I mean (Susie)

Wanting to find out who their sibling was and how he/she saw the world featured strongly in three of the interviews and to a lesser extent in two others. Getting to know more about the disability was linked to improvements in the sibling relationship. Although their sibling's disability was always present, participants felt that the disability didn't identify their sibling and their relationship.

I like the aspect of you can look at X from the outside but with some more knowledge you can understand what is going on on the inside (James)

I wouldn't think, 'Oh I have got a sister with a disability', I just think she is my sister (Clara)

Participants showed high levels of empathy and being able to take their sibling's viewpoint. They were able to give insights into the personality of their sibling despite the physical separation. Participants seemed to express ambivalent feelings in regards to the physical separation. Ambivalence related to their emotional and practical involvement. Participants all stressed a wish for more contact while also mentioning that this seemed to be difficult or unrealistic considering own life commitments such as work, friends, school or travelling.

I don't think I am in her life as much as I should be (...) I am kind of worried cause obviously I am going to go off and do my own thing. Maybe go to uni and stuff so I probably not going to see her probably hardly ever, so I am kind of hoping that I will stay in a place where I am near her (Lisa)

Current Life: Self

Adolescence seemed to be a turning point and an age at which participants became aware of future caretaking responsibilities and guardianship.

I was becoming aware of the fact that I would probably would have to be looking after him at some point in our lives (...) so I guess I had a sudden understanding or a need for an understanding (James)

However, this was still embedded in a strong experience of living in the present and long-term plans were abstract and difficult for participants to anticipate or relate to. There were differences across participants related to their specific context. Living at home, and seeing their mother daily, appeared to be linked to being more informed and visiting more often.

There were variations across participants in regard to views on their own future needs and supporting their sibling. Although all saw themselves involved and taking on more responsibility, their own needs in relation to life changes in young adulthood such as travelling, university and starting to be more independent were experienced as being in conflict or important to be considered alongside.

Current Life: Sibling

For one sibling, a residential placement in an adult provision had been identified but for all other siblings, long term plans around transitions into adult services were unclear. All participants were aware that their brother or sister's placement was going to come to an end at some point and adult services would take over. Yet, this seemed to be thought about in very abstract terms.

Participants knew about their sibling's life through visits and contact with the placement. Some participants described very close links to the residential school and how this had helped them to feel closer to their sibling.

(…) At first I think I was a bit scared and nervous just because I was quite young but looking back now even after a month I would wander about the corridors of the

school like it was my own school (Clara)

Positive aspects of the placements included peer-groups and cultural activities, a decrease in challenging behaviour, their sibling appearing happier in general and progress in education and learning new skills.

Awareness of the future

The future was discussed in relation to wishes and concerns participants had for their own and their sibling's future life. As mothers were very likely to still carry most responsibilities participants didn't anticipate a change in their responsibilities in the very near future or they saw this as a slow and naturally occurring process.

In all cases but one participants had agreed to sign or had already signed Guardianship agreements. Discussions of Guardianship appeared to be informal, with participants not conveying any doubts about accepting this responsibility in due course.

Mum just kind of came to me one day and was like oh, I am going to get forms sent through that if anything happens to me X will be kind of come into your care, but then I never really questioned it, it was just like yeah that's fine. So I don't actually know how it came up (Clara)

Exploring details of the Guardianship role during interviews appeared to make participants feel more insecure and three participants expressed needing more support and information about their role in the future. Most appeared confident to offer ongoing support through visits and care involvement but seemed to feel unclear in

regards to dealing with professionals. Involvement of Local Authorities and Social Work was experienced as being focused on costs. Concerns about future placements, in terms of educational needs, progress and further development, emerged strongly from all interviews.

I am not sure I think like I don't know, I am not sure about the process (…) Oh aye it had to go through a court process and all that. But I think it was about getting funding and stuff (Brian)

I think there is an inclination for people to at the age of 18 finish school, I guess the normal population feel it is on you to then develop, whether it be in employment or in further education, whereas obviously X doesn't have that motivation but I still think it is important that he develops while he is young and there is still kind of plasticity and he has that ability (James)

All participants expected their siblings to continue within residential care. An ideal future placement for participants' brothers and sisters seemed to integrate aspects of community living, peer-groups and social and cultural activities, meaningful work, educational activities, openness, involvement of families in addition to an understanding of their sibling's individual needs.

Discussion

Participants in this study described their experiences as a unique opportunity of

learning and appreciated what it had taught them. Participants seemed to express a more complex view of their experience than simply expressing it in either positive or negative terms. This supports the more nuanced perspectives of more recent studies, as opposed to the deficit focused studies that dominated the initial literature in this area (Burke *et al.* 2012; Gardiner & Iarocci 2012).

Participants seemed to draw little from outside support, contrasting with findings relating to general aging that see an increase in peer support during adolescence and young adulthood and a decrease in family attachments (Helsen *et al.* 2000; Turner 1999). The experience of isolation and difference has been identified primarily within studies involving children (Dodd 2004; Meyer 1993). Lack of understanding from peers has been linked to emotional distress for siblings (Petalas *et al.* 2009) while a need to better understand processes of accepting a different way of being has been highlighted in studies on the wellbeing of families (Moyson & Roeyers 2012).

When discussing conflicts between normality and difference, family seemed central within participants' accounts. This is reflected in recent findings that family functions as the main support system for individuals with intellectual disability (Robinson *et al.* 2015; Taggart *et al.* 2012). None of the participants mentioned support by friends, professionals or sibling support groups. Moreover, at a time where policies and legislations support higher community involvement (Heslop & Abbott 2007; DoH 2007) and collaborative practice (The Scottish Government 2013), it seems relevant to explore the realities of people's experiences .

Previous research has usually involved adults with siblings living at home. In this

context, this study set out to examine differences or commonalities of the experience of adolescence and residential placements. Adolescence and young adulthood stood out as a time of change in perspective. It appears that adolescence is an age in which participants become aware of future responsibilities. Yet, awareness was abstract and participants in this study were less concerned about future responsibilities. This contrasts with other studies which have found that, for many adult siblings, future involvement is connected with anxieties and questions about the impact on their adult lives (Davys *et al.* 2015; Eisenberg & Baker 1998; Harland & Cuskelly 2000). It is perhaps the case that the physical distance between siblings is a moderating factor in the anticipation of future need.

It has been suggested that parents feel ambivalent in wishing their children to accept their roles, once they feel unable to carry out these responsibilities, while at the same time not wanting to burden their children (Davys 2013). As such, it is interesting that those participants who were more involved discussed this subject in positive terms and felt better prepared for future responsibilities. Meanwhile some participants with less involvement, stated a wish to know more. Communication within families appeared to have less of a conscious component. Similarly, Davys (2013) found that although conversations seem to take place within families, members seem to have different, and at times conflicting, views as has been found by others (Krauss *et al.* 2005).

It was notable that experiences of ambivalence, in terms of conflicting feelings within themselves, was apparent across participants. Specifically, within their own narratives, participants described themselves as: (i) identifying as one family yet

living apart, (ii) feeling close, yet wishing to understand their sibling better, (iii) experiencing guilt whilst being supportive of the residential placement, (iv) wishing more involvement, yet having more personal life commitments (v) being positive about the future, whilst associating involvement with fights and struggles, and (vi) emphasising the normality of the experience, whilst also feeling different and isolated from peers. This highlights the complexity of the relationship between siblings within this study.

As the participants within this study spanned the transition between adolescence and adulthood, participants were more aware that this was a time when their own pathways and that of their sibling's began to differ significantly. As participants talked about living away from home or starting their own lives and careers they also talked about the need for networks for their siblings outwith the family. For example, participants seemed to acknowledge the importance of their sibling's placement in terms of development and academic achievement, as well as providing a sense of belonging outwith the family for their brother or sister. In the context of residential placements, siblings see support networks to be of even greater importance, given the higher level of dependency of individuals.

Within the present study, participants placed particular importance on the manner in which their sibling's residential placement offered their sibling improved peer networks and meaningful activities. In contrast to the account of participants, research has typically associated residential placements with less access to social and cultural life (Hallam *et al.* 2002; Kamstra *et al.* 2014; Luijkx *et al.* 2015; Zijlstra & Vlaskamp 2005). Participants within this study did not perceive this to be the case for their

siblings. This identifies a specific limitation in generalisability of our study. Our focus was upon one residential setting, which may not reflected the wider experiences of those in residential care.

All siblings were in a residential setting with a strong educational and vocational emphasis. In the participants' narrative the current placements seemed to be characterised by qualities of community, openness, vocation and peer groups; and participants raised wishes for those qualities to be present in future care arrangements. Gillet and Stenfert-Kroese (2003) arrived at similar conclusions on the links between the organisational culture of residential placements and the wellbeing of individuals with learning disabilities. This points to a need to better understand the qualities within service-delivery that are related to better quality of life for those individuals in residential placements.

Limitations

It might be said that this study is limited by its qualitative design, and therefore not generalisable. However, given the complexity of this area, an IPA design was considered to be most appropriate. Nonetheless, participants were recruited from one single service and different models of care might result in different findings. Themes generated are acts of interpretation on part of the researcher and are drawn from a small group; hence, generalisations should be made cautiously and considered alongside the existing knowledge base.

Conclusion

Overall, this study highlights the complex relationship between siblings when one is in residential care. For the sibling without the intellectual disability, there is an

overarching sense of ambivalence about the placement of their brother or sister. The benefits of residential care are expressed, but so also are feelings of guilt about this. Concerns about the future appear less prominent than in other studies where siblings reside together. This perhaps reflects the physical distance between the siblings, rather than an appraisal of true future care needs. A feeling of isolation and 'difference' from their peers, and a desire for greater information about their sibling's needs, suggests that there is a need to develop support for those whose siblings are placed in residential care.

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